

**EXAMINING THE PSYCHOSOCIAL IMPACT OF
HUMAN PAPILLOMAVIRUS OROPHARYNGEAL
CANCER**

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A thesis submitted for the degree of Doctor of Philosophy

University College London

DECLARATION

I, Rachael Dodd, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm this has been indicated.

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Firstly, I owe a great deal of thanks to my three supervisors, Jo Waller, Laura Marlow and Alice Forster for being a constant source of support and encouragement, even when I approached them with the most minor questions. I would also like to acknowledge Jane Wardle, who prior to sadly passing away last year, was one of my supervisors. I have so much admiration for Jane and she has left an incredible legacy at the Health Behaviour Research Centre.

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ABSTRACT

The causal role of human papillomavirus (HPV) in oropharyngeal squamous cell carcinoma (OSCC) has been well established. The work presented in this thesis sets out to explore the information available about HPV-OSCC and examine the psychosocial issues associated with a diagnosis of HPV-OSCC.

Six studies were carried out between 2013 and 2016. Study 1 systematically reviewed the existing literature examining the psychosocial impact of HPV-OSCC in patients (n=10 studies) and current knowledge of the relationship between HPV and OSCC (n=41 studies). Study 2 was a content analysis examining the media coverage in the UK of the link between HPV and OSCC (n=112 articles). Study 3 was a qualitative study with health professionals caring for HNC patients (n=15). Study 4 was an extension of study 3, developing a survey for dissemination among health professionals working with HPV-OSCC patients (n=260). Both studies explored their experiences of and attitudes to discussing HPV with their patients, with study 4 additionally measuring knowledge of HPV-OSCC. Study 5 was a qualitative study with patients diagnosed with HPV-OSCC (n=20) and with some of these patients' partners (n=12), examining their experiences around the diagnosis of HPV-OSCC. Study 6 involved the development of an information booklet about HPV-OSCC, based on the findings of studies 1-5.

The existing literature examining the psychosocial impact of HPV-OSCC provided limited evidence about the impact of HPV in OSCC patients. Knowledge of HPV in OSCC was not well known across most populations, and the HPV-OSCC content presented in the media lacked basic facts about HPV. The increasing incidence of HPV-OSCC was a significant issue for health professionals and key messages to communicate to HPV-OSCC were found. Reactions about HPV were mixed among participants whose cancer or partners' cancer was caused by HPV. An information booklet developed about HPV-OSCC was well received by patients and health professionals and could act as a discussion tool to provide patients with evidence-based information. De-escalation of treatment in the future may help minimise some of the negative psychosocial outcomes associated with HPV-OSCC and improve long-term functioning.

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LIST OF ABBREVIATIONS

CD4	Cluster of differentiation 4
COM-B	Capability Opportunity Motivation-Behaviour model
CSM	Common Sense Model
DNA	Deoxyribonucleic acid
EORTC	European Organisation for Research and Treatment of Cancer
FFPE	Formalin-fixed paraffin-embedded
GP	General Practitioner
HADS	Hospital Anxiety and Depression scale
HNC	Head and neck cancer
HNQOL	Head and Neck Quality of Life
HRQOL	Health Related Quality of Life
HPV	Human papillomavirus
HPV-OSCC	Human papillomavirus-oro-pharyngeal squamous cell carcinoma
ICD	International Classification of Disease
IHC	Immunohistochemistry
IMB	Information-Motivation-Behavioural Skills model
ISH	In-situ hybridization
MSM	Men who have sex with men
NASCAR	National Association for Stock Car Auto Racing
NCCN	National Comprehensive Cancer Network
NHANES	National Health and Nutrition Examination Survey
NHS	National Health Service
NS	Not significant
OSCC	Oropharyngeal squamous cell carcinoma
PAG	Participatory Advisory Group
PCI	Patient Concerns Inventory
PCR	Polymerase chain reaction

PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QOL	Quality of life
RCT	Randomised controlled trial
RNA	Ribonucleic acid
SCC	Squamous cell carcinoma
SD	Standard deviation
TDF	Theoretical Domains Framework
TNM	Tumour Node Metastases
UCL	University College London
UK	United Kingdom
USA	United States of America
UWQOL	University of Washington Quality of Life scale
WHO	World Health Organisation

CHAPTER 1. EPIDEMIOLOGY

Human papillomavirus (HPV), the leading cause of cervical cancer, has increasingly been recognised as a cause of head and neck cancer (HNC). The increasing number of HPV-related HNC cases have implications both for health professionals in clinical practice, for the patient and for the patient's family. There is a depth of understanding of the role of HPV in cervical cancer, but as yet, in comparison there is still a sparse amount of understanding of the natural history of HPV in HNC and a lack of research examining the psychosocial impact of a diagnosis of HPV-related HNC. The term 'psychosocial' is used throughout this thesis in reference to cognitive, social, emotional and behavioural implications of the diagnosis of HPV.

This chapter presents the epidemiology and risk factors of both HNC and HPV-related HNC, and what implications this might hold for treatment of HNC patients in the future. Chapters 2 and 3 will present evidence of the psychosocial impact of HNC and of HPV in the context of cervical cancer screening. Theoretical approaches which may be useful for future research will also be considered.

1.1 Head and neck cancer

The term HNC covers cancers found in the lip, oral cavity, nose and paranasal sinuses, nasopharynx, oropharynx, hypopharynx and larynx (Syrjanen, 2004). HNCs are usually found in squamous cells that line the moist, mucosal surfaces inside the head and neck. This includes the mouth, nose and throat. Therefore the most common type of HNC is squamous cell carcinoma (SCC), accounting for about 90% of HNCs (Kim, King, & Agulnik, 2010). HNC is the sixth most common type of cancer in the world, with approximately 600,000 new cases diagnosed worldwide each year (Ferlay et al., 2010).

1.1.1 Terminology

As described above, the term HNC encompasses a range of anatomical sites in the head and neck. The term HNC covers all cancers of the head and neck, whereas other terms such as oral cancer, mouth cancer, throat cancer and oropharyngeal cancers include specific anatomical sites. These terms are often used interchangeably and although oropharyngeal cancer will be

the type of HNC that will be focused on throughout this thesis, some of the studies did not specifically recruit using oropharyngeal cancer as a criterion and so for these studies, the broader term of HNC has been used to encompass all cancers of the head and neck. Also when citing previous research, the term will be dependent on the type of cancer presented in the study.

Figure 1.1 illustrates the parts of the head and neck where oropharyngeal squamous cell carcinoma (OSCC) occurs and Table 1.1 demonstrates which anatomical sites are included in the different terminologies. The International Classification of Diseases (ICD) was produced by the World Health Organisation (WHO) and provides a diagnostic tool for epidemiology, health management and clinical purposes. The ICD-10 is the latest version of the diagnostic tool and Table 1.2 clarifies the codes assigned to HNCs, with those codes assigned to OSCCs in bold.

1.1.2 Oropharyngeal cancer

Oropharyngeal cancers are those HNCs located in the soft palate, base of the tongue, side walls of the throat (tonsils) or the back wall of the throat (Macmillan Cancer Support, 2013). SCCs account for the majority of oropharyngeal cancers. Symptoms can include a painless swelling or lump in the neck, a sore throat or tongue, earache, difficulty swallowing or moving the mouth and jaw, changes in a patient's voice, bad breath and unexplained weight loss (Macmillan Cancer Support, 2013).

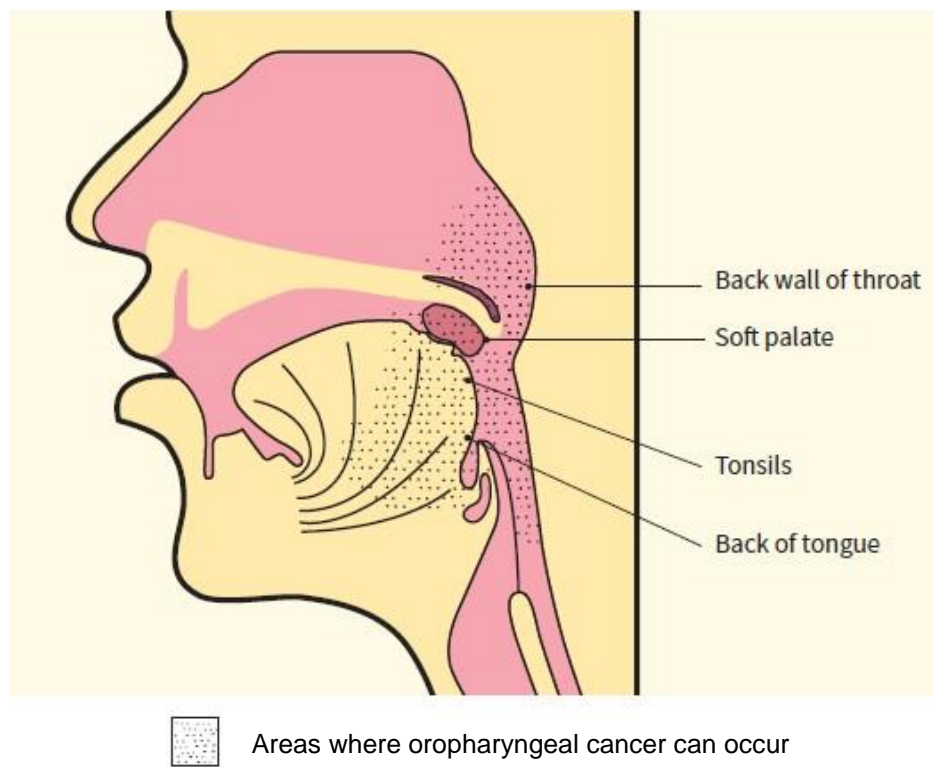


Figure 1.1: Showing the parts of the head and neck where oropharyngeal cancers occur

Table 1.1: Explaining the terminology behind the anatomical sites

Anatomical site	Common terminology				
	Head and neck cancer	Oral cancer	Oropharyngeal cancer	Mouth cancer	Throat cancer
Oral cavity (including lip, floor of mouth, buccal mucosa, gingiva, hard palate and mobile part of the tongue)	x	x		x	
Nose and paranasal sinuses	x				
Nasopharynx	x				x
Oropharynx (including base of tongue, tonsils, soft palate, back wall of throat)	x	x	x		x
Hypopharynx	x	x			
Larynx	x				x
Laryngopharynx					x

Table 1.2: International Classification of Diseases for head and neck cancer

ICD-10 code	Site description
C00-C14	Malignant neoplasm of lip, oral cavity and pharynx
C00	Malignant neoplasm of lip
C01	Malignant neoplasm of base of tongue
C02	Malignant neoplasm of other and unspecified parts of tongue
C03	Malignant neoplasm of gum
C04	Malignant neoplasm of floor of mouth
C05	Malignant neoplasm of palate
C06	Malignant neoplasm of other and unspecified parts of mouth
C07	Malignant neoplasm of parotid gland
C08	Malignant neoplasm of other and unspecified major salivary glands
C09	Malignant neoplasm of tonsil
C10	Malignant neoplasm of oropharynx
C11	Malignant neoplasm of nasopharynx
C12	Malignant neoplasm of pyriform sinus
C13	Malignant neoplasm of hypopharynx
C14	Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx
C30	Malignant neoplasm of nasal cavity and middle ear
C31	Malignant neoplasm of accessory sinuses
C32	Malignant neoplasm of larynx

The codes in bold are those assigned to OSCC

1.1.2.1 Staging

When diagnosing oropharyngeal cancer, the stage of the tumour influences treatment options and prognosis. Table 1.3 shows the Tumour Node Metastases (TNM) staging given to oropharyngeal cancers. This staging system includes Tumour (T) stages for the size of the primary tumour and whether this has spread to any tissues of the oral cavity or oropharynx, Node (N) stages for the extent that the cancer has spread to regional lymph nodes, and Metastases (M) stages for whether the cancer has metastasised (spread to other parts of the body). The numbers that appear after the stages indicate the degree of severity, from 0-4 for T stage, 0-3 for N stage and 0 or 1 for M stage, with the greater the number indicating greater severity. When each of these stages have been summarised, patients are given an overall stage for their cancer, which are dependent on combinations of TNM (Table 1.4). For example, if a tumour is small ($\leq 2\text{cm}$; T1 stage) and has not spread to nearby (N0 stage) or other parts of the body (M0 stage), then the patient would be diagnosed with early stage I cancer, whereas if the tumour is any size (any T stage), has or has not spread locally (any N stage), but has spread to distant sites (M1 stage), this patient would be diagnosed with advanced stage IVC cancer.

Table 1.3: TNM stages for oropharyngeal cancer: Information taken from <http://www.cancer.org/cancer/oralcavityandoropharyngealcancer/detailedguide/oral-cavity-and-oropharyngeal-cancer-staging> (American Cancer Society, 2014)

Table 1.4: Staging for oropharyngeal cancer: Information taken from <http://www.cancer.org/cancer/oralcavityandoropharyngealcancer/detailedguide/oral-cavity-and-oropharyngeal-cancer-staging> (American Cancer Society, 2014)

1.2 Risk factors for HNC

1.2.1 Traditional risk factors of HNC

Causes of HNC are traditionally known to be related to lifestyle, such as through the consumption of tobacco and alcohol. The typical patients are older men (>65) (Hammerlid, Persson, Sullivan, & Westin, 1999) of lower socioeconomic status (Conway et al., 2008). Studies have shown over half of HNCs in the UK are caused by smoking (Parkin, 2011b) and almost a third are caused by drinking alcohol (Parkin, 2011c). More common in Asia, chewing tobacco or betel quid is also known to cause HNC. Studies have shown that the risk of HNC decreases with increasing time since giving up smoking or drinking alcohol (Marron et al., 2010). Alcohol and smoking remain the most important causes of HNC worldwide (Serra-Majem, 2016; Soerjomataram, De Vries, Pukkala, & Coebergh, 2007).

Poor diet and poor dental hygiene have also been shown to be risk factors for HNC, but as these are also usually associated with areas of lower socioeconomic position, it is difficult to rule out this as a confounding variable (Gillison, 2007; Guha et al., 2007).

1.2.2 Human papillomavirus

Human papillomavirus, or HPV as it is more commonly known, is a common sexually transmitted infection which can be contracted through both skin-to-skin and sexual contact. There are over 100 variants of HPV (Parkin, Bray, Ferlay, & Pisani, 2005). High-risk carcinogenic types of HPV include HPV16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 68, 73, and 82 (Munoz, Bosch, Sanjosé, Herrero, & Castellsagué, 2003), with HPV16 and HPV18 being the most well recognised. High-risk sexually transmitted HPV types are thought to be responsible for up to 5% of cancers worldwide, including cervical, anal, penile, vaginal, vulva and some OSCCs (Parkin & Bray, 2006). Those classified as low-risk such as HPV6 and 11 are rarely associated with malignant disease and are implicated as causes of genital warts. In anogenital HPV, most people clear high-risk types within a year and low-risk types in less than a year (Schiffman & Kjaer, 2003). Most sexually active people will contract HPV at some point in their lives (Fakhry & D'Souza, 2013).

1.2.2.1 HPV-positive head and neck cancers

First suggested in 1983 (Syrjänen, Syrjänen, Lamberg, Pyrhönen, & Nuutinen, 1983) the aetiological role of HPV in OSCC has now been well established through epidemiological studies (Gillison et al., 2012; Mehanna, Beech, Nicholson, El-Hariry, & McConkey, 2013; Näsman et al., 2009; Rietbergen et al., 2013). Studies found associations between HPV and HNC as early as 1997 (Paz, Cook, Odom-Maryon, Xie, & Wilczynski, 1997), with a study in 1998 specifically finding HPV16 to be associated with OSCC (Wilczynski, Lin, Xie, & Paz, 1998). A seminal study confirmed the causal association of HPV in OSCC, through a retrospective analysis of tumour tissues of patients diagnosed with HNC (Gillison et al., 2000). The rate of HPV in the oropharynx has been shown to be consistently higher than in the oral cavity, larynx or hypopharynx (Sturgis & Cinciripini, 2007). A large international study found 22.4% oropharyngeal, 4.4% oral cavity and 3.5% larynx were HPV-positive and that HPV16 was largely the most common type (Castellsagué et al., 2016). A meta-analysis of 60 studies across 26 countries showed 26% of 5046 HNC cases were HPV-positive. HPV was found in 36% of OSCCs, 23% of oral cancers and 24% of laryngeal cancers (Kreimer, Clifford, Boyle, & Franceschi, 2005). The tonsil and the base of tongue are the two areas of the oropharynx where HPV is more commonly found and are the tumour sites responsible for the increasing proportion of OSCCs (Dahlstrom et al., 2013). One explanation for this is that the properties of the mucosa found in these areas is similar to that of the properties of the mucosa in the cervix (Kreimer et al., 2005).

HPV-OSCC appears to be biologically and clinically distinct from other HNCs (Marur, D'Souza, Westra, & Forastiere, 2010) and although the natural history of oral HPV is not well understood, it is thought to differ from that of cervical HPV (D'Souza, Kreimer, et al., 2007). Studies examining the persistence of oral HPV over time have been with limited numbers of participants and have not analysed by HPV-type, so have been unable to estimate the incidence or clearance rates of oral HPV (D'Souza, Fakhry, et al., 2007). Risk factors for oral HPV have also been shown to significantly differ from cervical HPV. There is no established clinical infrastructure for screening or for the understanding of precancerous lesions, unlike in cervical cancer. There is still much to learn about HPV-OSCCs, in particular about its natural history and its progression from oral HPV to HPV-OSCC.

HPV-positive patients typically present at an advanced nodal stage (see

Table 1.4) (Gillison et al., 2008; Khode, Dwivedi, Rhys-Evans, & Kazi, 2014) and as a result have stage IV disease. This may be due to the challenges associated with the distinct nature of HPV-OSCC from other HNCs, being asymptomatic, and the changing demographic of patient without the common risk factors. T and N stage combined with smoking history are the most important prognostic factors (Ang et al., 2010; O'Sullivan et al., 2013) in the TNM staging system. Health professionals may lack suspicion of HNC due to the patient having a negative smoking history and there may be an absence of signs and symptoms in early disease. Other delays may occur due to inadequate training or equipment and detection methods (Lewis et al 2015). It is therefore important for health professionals to not be dismissive of younger patients (~ 55 years of age) (Dahlstrom et al., 2013) who present to their general practitioner (GP) with potential symptoms of HNC such as a sore throat, a swelling or a sore that does not heal, and who are either non-smokers or non-drinkers. These patients should be considered highly suspicious for HPV-OSCC (Gillison et al., 2000).

Despite TNM staging characterising many of these tumours as locoregionally advanced, the prognosis for these cancers caused by HPV is more in line with earlier staged cancers which have not been caused by HPV (Paz et al., 1997). They have different causes, risk factors and survival outcomes. Recently, it has been recognised that a new staging system is needed for HPV-OSCC due to the better outcomes in these patients despite the advanced nodal stage and consequently, more advanced overall stage (Dahlstrom, Garden, William, Lim, & Sturgis, 2016). For HPV-positive HNC patients, the T stage has been shown to have more prognostic value (Ward et al., 2015) and for HPV-negative HNC patients, the N category has been shown to have more prognostic value (Hong et al., 2013). Table 1.5 illustrates some of the distinct differences between HPV-positive and HPV-negative HNCs.

Table 1.5: Comparison of HPV-negative and HPV-positive HNC

Characteristics	HPV-negative	HPV-positive
Site	All sites	Tonsil, base of tongue
Risk factors	Tobacco/alcohol	Sexual behaviour
Co-factors	Poor oral hygiene	Marijuana use
Age	Older cohorts	Younger cohorts
Sex	3:1 men	3:1 men
Incidence	Decreasing	Increasing
Stage	Variable	Early T stage, advanced N stage
Histology	Keratinized	Basaloid/poorly differentiated
p16	Decreased expression	Increased expression

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HPV-OSCCs occur more in men than women, with a ratio of 3:1, but this ratio varies across countries (Combes, Chen, & Franceschi, 2014). The typical patients are younger (<65), white men, married, educated and employed (Gillison et al., 2008; Marur et al., 2010). Patients tend otherwise to be in good health, without any traditional risk factors or comorbid disorders (Gillison et al., 2008; Lin et al., 2013; Marur et al., 2010). Although lower rates of smoking are seen among HPV-OSCC patients, many patients are current or former smokers (60-70%) and true non-smokers account for the minority (Ang et al., 2010; Gillison et al., 2012; O'Sullivan et al., 2013).

The evidence presented shows the changing demographic of HNC patients and how HPV-related OSCC is clinically and biologically distinct from other HNCs. These studies also demonstrate that there is still a lot that is not known about HPV-OSCC.

1.2.2.2 Risk factors for HPV-related HNC

Sexual behaviour

Moving on to look at the risk factors associated with HPV-OSCC, a number of studies have found a greater lifetime number of sexual (>26) and oral sex partners (>6) to be associated with increased risk of oral HPV infection (Blomberg, Nielsen, Munk, & Kjaer, 2011; D'Souza, Agrawal, Halpern, Bodison, & Gillison, 2009; D'Souza, Kreimer, et al., 2007; Fakhry, Gillison, & D'Souza, 2014; Farsi et al., 2015; Gillison et al., 2008) due to greater exposure to HPV. In a cross-sectional study with a control patient group from an outpatient otolaryngology clinic as one population and university students as a second population, evidence of oral HPV infection was found in oral samples of men who reported never having oral sex (D'Souza et al., 2009), suggesting that oral sex may not be the only route of transmission for oral HPV infection. The results from this study are not population-based and can therefore not be generalised, however the authors did find comparable levels of sexual activity in these samples compared to a large population based study discussed below.

The National Health and Nutrition Examination Survey (NHANES) is a large population-based USA study which detected oral HPV through oral samples of over 2000 men and 2000 women and sexual behaviour information through an audio computer-assisted interview. Men were found to have a significantly higher number of lifetime oral and vaginal sexual partners compared to women and to have a higher prevalence of oral HPV16. Although men and women aged 30-59 were more likely to have performed oral sex compared to those 60-69, oral HPV16 prevalence was similar (D'Souza, Cullen, Bowie, Thorpe, & Fakhry, 2014). This study concluded that oral sexual behaviour was the primary predictor of oral HPV16 infection, as after oral sexual behaviour was controlled for, age-cohort and race were no longer associated with oral HPV16.

It has been hypothesised that performing oral sex on a woman results in a higher level of oral HPV exposure compared to oral sex on a male because of the viral load of HPV being higher in the female genital mucosa than the male genital mucosa/skin (Pytynia, Dahlstrom, & Sturgis, 2014). It was also thought that there may be some differences in local immune responses in the cervix and oral cavity of women which may explain the differences in prevalence of oral and cervical HPV and consequent oral exposure to infection (Fakhry et al., 2013). Another study using data from the NHANES found that for each additional sexual partner, men were at a

three-fold greater risk for high-risk oral HPV than women, supporting the hypothesis of higher transmission rates from females to males than from males to females (Giuliano et al., 2015). These authors report on a series of five longitudinal studies which have shown the transmission of HPV from men to women to have a lower incidence than from women to men. Prevalence of oral HPV also plateaued at different stages for men and women, being approximately 15 oral sex partners for men and approximately five oral sex partners for women, demonstrating there is a lower threshold at which point prevalence does not increase among women. This is hypothesised to be due to natural seroconversion rates of HPV being higher in women than in men, potentially due to greater exposure to genital HPV. The differences in HPV-OSCC prevalence between men and women may also be due to men smoking more heavily (see below) and for longer durations than women (Combes et al., 2014).

Open-mouthed kissing is also thought to be a route of transmission for HPV (D'Souza et al., 2009; Pickard, Xiao, Broutian, He, & Gillison, 2012), specifically having at least 16 open mouth kissing partners (Fu et al., 2015). These studies were all carried out with university students and so may not be representative of the general population, but could be representative of student populations. These results need to be replicated in a general population-based study.

Smoking

Another factor which has been shown to raise the odds of persistent oral HPV is current smoking (D'Souza, Kreimer, et al., 2007; Kreimer & Chaturvedi, 2011). Oral HPV16 prevalence has been found to be greater in current tobacco users compared with never or former tobacco users (Fakhry, Gillison, et al., 2014), having been shown to have immunosuppressive effects (Sopori, 2002). Higher odds of HPV were found in current than never smokers (Anantharaman et al., 2016), but smoking increased the risk of OSCC independent of HPV status. Current tobacco users were also found to be more likely to have other risk factors for HNC as they were male, younger, less-educated and had a higher number of oral sexual partners (Fakhry, Gillison, et al., 2014).

Human Immunodeficiency Virus (HIV)

Studies with HIV patients have indicated that HIV may increase the persistence and progression of HPV-related HNC (D'Souza, Carey, et al., 2014; Picard et al., 2016). Having a CD4 (white blood cells which organise the immune system's response to bacterial, fungal and viral infections) count of <500 (and therefore showing some damage to your immune system) have been shown to be associated with persistence of oral HPV infection (D'Souza, Fakhry, et al., 2007). D'Souza and colleagues found HPV detected in 30% of HIV HNCs and 64% of OSCCs. HIV-positive HNC patients were also more likely to be male, younger, nonwhite and current smokers (D'Souza, Carey, et al., 2014) showing some similar attributes to the general population for both HPV-related and tobacco or alcohol-related HNCs.

In summary, sexual behaviour is thought to be the most important risk factor for HPV-OSCC, with smoking and HIV having potential interactive affects.

1.2.3 Determining oral HPV status in tumours

Focusing on the different methods used to determine the HPV status of a tumour, an important finding is that the biology of HPV-OSCC is distinct from HPV-negative HNC (Neuens & Nuyts, 2015). A few different methods are currently being used to determine the HPV status of a tumour. In-situ hybridization (ISH) uses histology specimens to identify specific segments of nucleic acids and specific DNA or RNA sequences and has moderate sensitivity but high specificity (Schlecht et al., 2011). Polymerase chain reaction (PCR) involves testing the DNA of biopsy specimens for HPV and has high sensitivity but low specificity (Jung et al., 2010). As a surrogate test immunohistochemical (IHC) involves staining for p16 and has high sensitivity but moderate specificity (Jordan et al., 2012). There is no 'gold standard' test, but the most commonly used tests are ISH and PCR, with HPV DNA methods being found to be the most objective and reliable (Bussu et al., 2014). p16 IHC is widely used in clinical practice (Neuens & Nuyts, 2015) as p16 is commonly used as a surrogate marker for HPV. p16 expression has been found to occur in a small percentage (5-8%) of HPV-negative head and neck SCCs (Liang et al., 2012) demonstrating that this method is not always reliable.

Testing for HPV is not routinely carried out in the UK, but recent guidelines have been published for doing so (National Institute for Care and Excellence, 2016), as there are in the USA (Pfister

et al., 2012). The UK and USA recommend testing the tumour for HPV using IHC staining for p16. In Canada, Cancer Care Ontario has recommended that all adult patients with OSCC should be tested for HPV and as p16 ISH has demonstrated high sensitivity, that HPV status in OSCC should be determined using this method (Lacchetti et al., 2013).

Although HPV is being tested for more routinely, treatment and care methods are not currently being modified on the basis of HPV status unless patients are enrolled into clinical trials. Also, the mere presence of HPV DNA in these methods is not enough for causality to be established; the detection of oncogenic proteins in HPV and events such as p16 overexpression is essential for inferring causality.

1.2.4 Prevalence of oral HPV infections

General population

Now considering methods to determine oral HPV in a healthy population, there is no 'gold standard' test, but those commonly used are oral swabs/scrapes, oral rinses and saliva samples. Prevalence rates range dependent on the oral sampling method used, from 6.9% using oral scrapes (Herrero et al., 2003) to 18.3% with saliva samples (Montaldo et al., 2007).

A systematic review of oral HPV prevalence in healthy individuals included studies that detected oral HPV DNA in around 4000 cancer-free participants and estimated prevalence of 4.5% for any HPV infection and 1.3% for oral HPV16 (Kreimer et al., 2010). Oral HPV16 accounted for 28% of HPV detected in the oral region. Estimates of the prevalence of any oral HPV infection from other studies range from 1.0% and 1.6% in healthy males (Kreimer et al., 2011) to 2.4% in a sample of young (aged 18-30) men and women (Pickard et al., 2012). At any given time, it has been estimated that approximately 7% of the USA population has an oral HPV infection (Gillison et al., 2012; Pickard et al., 2012). These are estimates and the variations in prevalence are likely due to different testing methods, as described above.

In a population-based, cross-sectional study in the USA, a bimodal distribution was found for the prevalence of oral HPV infection in over 5,500 participants (Gillison et al., 2012). The overall prevalence of oral HPV infection between 2009 and 2010 was 6.9% and prevalence of oral HPV infection peaked in the 30-34 and 60-64 age groups. Prevalence was also found to be higher in

men than women, for both any oral HPV infection and oral HPV16. It is not possible to compare these estimates across countries as they are not available.

HPV-OSCC patients

Looking at the prevalence of oral HPV infection in OSCC patients, a large study in the USA using cancer registry data found oral oncogenic HPV infection to peak bimodally at 25-30 years and at 50-60 years, with a median age of 63 at diagnosis (Chaturvedi, Engels, Anderson, & Gillison, 2008). This led the authors to estimate a latency period between oral HPV infection and an HPV-OSCC diagnosis of approximately 10-30 years, under the assumption that either peak in prevalence could contribute to risk.

In the United States, HPV is detected in two thirds of OSCCs (American Cancer Society, 2013) and the high-risk type HPV16 has been implicated in over 90% of HPV-positive tumours (D'Souza, Kreimer, et al., 2007; Gillison et al., 2000). Only a small number are caused by other HPV types such as HPV18, 31, 33, 35, 52 and 58 (Chaturvedi et al., 2011) but the associations with other high-risk types remain unclear (Michaud et al., 2014). In patients with HPV16, HPV18 and HPV33 were found to be significantly associated with OSCC (Michaud et al., 2014). In the UK the number of OSCCs caused by HPV has been estimated at 14% (Parkin, 2011a) but this figure is now out-of-date. A few studies have demonstrated HPV16 infection to precede those later diagnosed with HPV-positive HNC. A Nordic cohort study showed in those patients later diagnosed with HNC, prevalence of HPV16 seropositivity was almost twice as high compared to control participants (Mork et al., 2001). This has also been found in other studies (Hansson et al., 2005; Smith et al., 2004).

It is difficult to assess prevalence rates over time as no large scale studies have followed the dynamics of oral HPV infection in the general population for longer than one year. The largest prospective study to date examined oral HPV infection among 1626 adult males with a median follow-up of 12.7 months (Kreimer et al., 2013). Four per cent of men had a new oral HPV infection, with a median duration of infection of 6.9 months, and less than 1% of men developed an oral HPV16 infection with a median duration of 7.3 months. The majority of infections had cleared or were below the threshold of detection by 18 months.

Summary

Prevalence studies show the overall prevalence of oral HPV is low, but the estimates can vary due to the different testing methods mentioned above and the populations it is measured in. Oral HPV has also been shown to demonstrate bimodal peaks at around 30 years of age and 60 years of age. Longitudinal studies are needed to assess how prevalence of oral HPV changes and also a reliable, standardised test is needed to detect oral HPV in both the general population and in the tumours of patients.

1.2.5 Concordance of oral and genital HPV

Some studies have investigated both oral and genital specimens to look for concordance between different anatomical sites and investigate whether HPV can be transmitted across the two sites. In a sample of over 2200 men in rural China, the prevalence of HPV in the oral cavity was 6.7% and 16.9% for the external genitalia (Liu et al., 2015). HPV was found in both in the oral cavity and the external genitalia of 43 men; 60.5% of these had an identical HPV type at both sites. The authors concluded that the risk of oral HPV infection was higher among men with genital HPV infection than among uninfected men, and that having multiple lifetime sexual partners was a significant risk factor for oral-genital HPV coinfection. In contrast, in a small sample (n=151) of HIV negative men who have sex with men (MSM) at a sexual health clinic in the UK, oral rinse and anogenital samples found prevalence of any oral HPV to be 13.7% and any anogenital HPV to be 64.9%. High-risk HPV types were found in 5.9% of oral HPV and 34.4% of anogenital samples (King et al., 2015). These authors found no concordance between HPV types detected in both oral and anogenital sites.

Another small sample (n=34 heterosexual couples) study taking place in South Africa at an HIV testing centre found similar oral HPV prevalence in women (12%) and men (18%) (Vogt, Gravitt, Martinson, Hoffmann, & D'Souza, 2013). Oncogenic HPV types were found in 4% of oral, 26% of penile and 74% of vaginal samples. HPV16 was found in 1% of oral, 12% of penile and 21% of vaginal samples. Thirty-five per cent of couples had at least one type-specific concordant vaginal-penile HPV infection, but only one of nine couples who had oral HPV, had concordant oral-oral infection. The concordance of oral-genital HPV infection was higher, with 67% of men and 25% of women with oral HPV infection having a partner with a concordant genital HPV infection. Data from this study supports the hypothesis of the transmission of vaginal HPV

infection to the oral cavity during oral sex. Another study found that partners of patients with HPV-OSCC have a similar prevalence of high-risk oral HPV infection to the general population (1.2%; D'Souza, Gross, et al., 2014).

It is important to carry out concordance studies to help us understand the risk of transmission among partners and from one body site to another. The limited data available currently is inconclusive and limited in its ability to generalise due to small samples and non-population based studies. The studies do demonstrate consistently that prevalence of oral HPV is lower than the prevalence of genital HPV.

1.3 Incidence rates and timeline of progression of HNC

1.3.1 Incidence of HNC

In the UK, approximately 11,200 new cases of HNC are diagnosed each year (ISD Scotland, 2013; Northern Ireland Cancer Registry, 2013; Office of National Statistics, 2013; Welsh Cancer Intelligence and Surveillance Unit, 2013), around 25% of which are classified as base of tongue, tonsil or OSCCs. The incidence of HNCs in the UK has increased over the last few decades and Figure 1.2 shows data from the cancer registries in England, Scotland, Wales and Northern Ireland. Incidence rates in England have risen by 58% from 1995 to 2011 (Louie, Mehanna, & Sasieni, 2015). Figures in Scotland have risen by approximately 51% from 1990 to 2014, in Wales by approximately 47% from 2001 to 2014 and by approximately 25% in Northern Ireland between 1993 and 2014. Figures for oral cancer show it was the 14th most common cancer in the UK in 2013, being the 11th most common cancer in males and the 16th most common cancer in females. One in 75 men and one in 150 women will be diagnosed with oral cancer during their lifetime (Cancer Research UK, 2016).

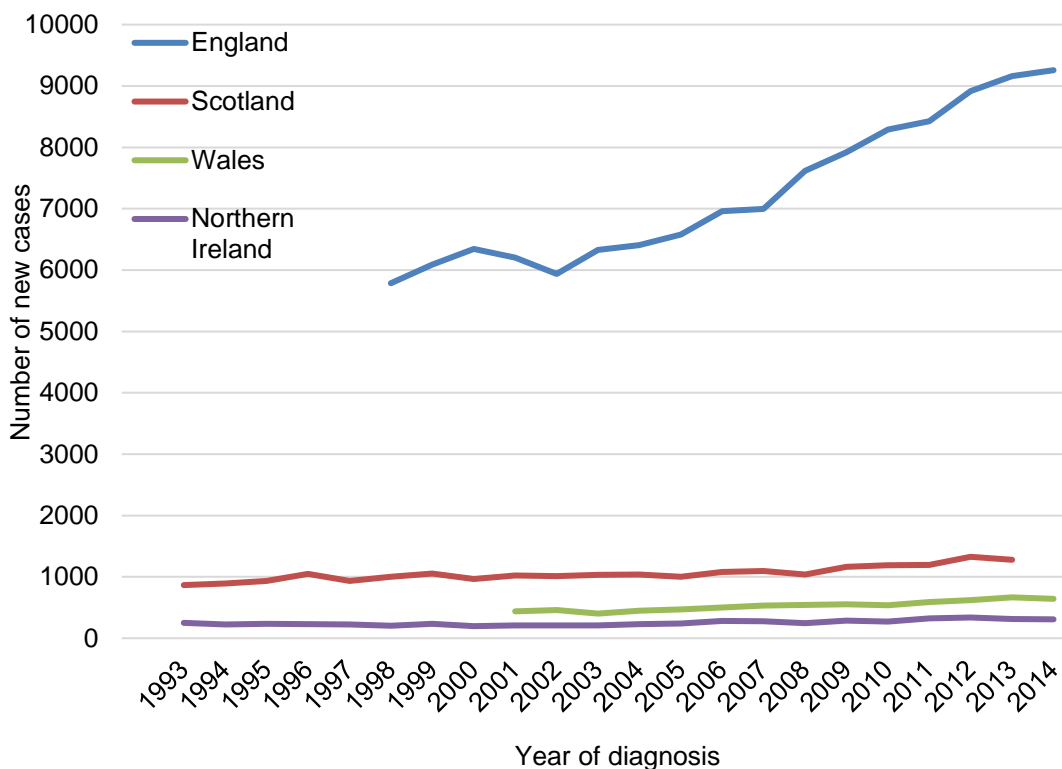


Figure 1.2: Incidence of head and neck cancers in the UK

Looking specifically at oropharyngeal cancers, figures for the incidence of oropharyngeal cancers in England and Scotland show an increase in the number of people diagnosed from 1998 to 2013 (Figure 1.3). In England the incidence of oropharyngeal cancers has risen more dramatically than for any other HNC and the increasing trend has paralleled that of genital warts and genital herpes (Louie et al., 2015). Figures for oropharyngeal cancers in England include ICD-10 codes C01, C09 and C10 and in Scotland, the cancer registry additionally included the codes C02.4, C05.1 and C05.2. Figures were not available separately for the ICD-10 codes relating to oropharyngeal cancers in Northern Ireland or Wales.

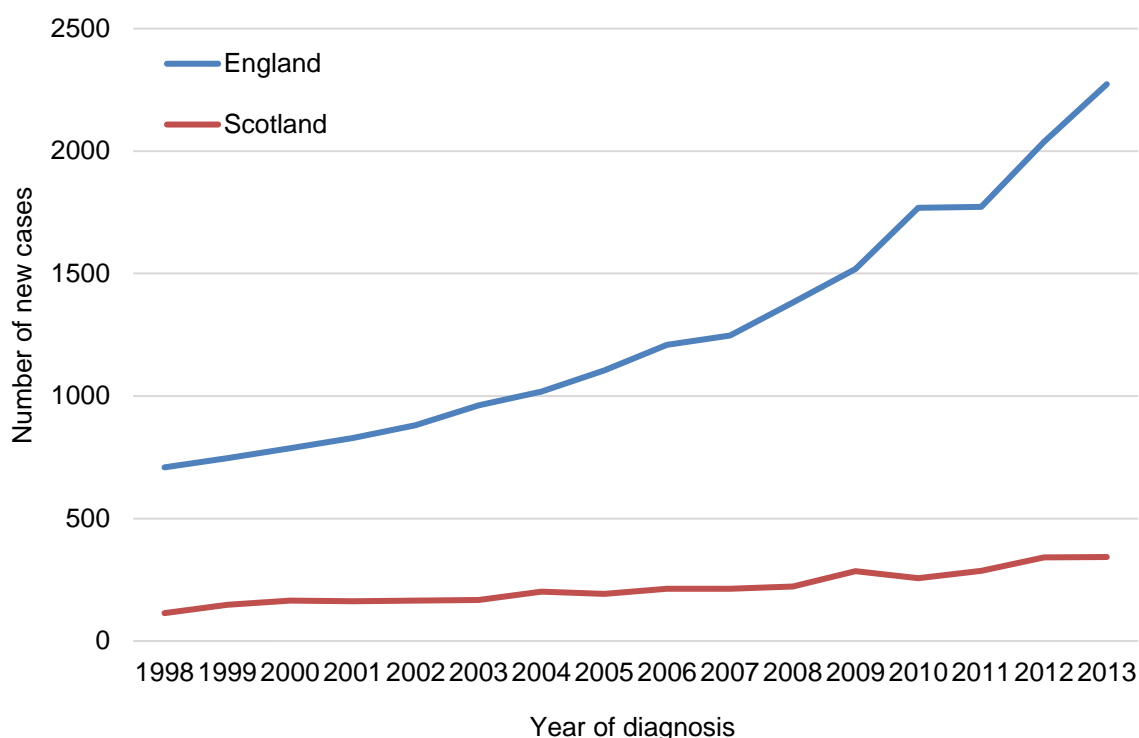


Figure 1.3: Incidence of oropharyngeal cancers in England and Scotland

The incidence of HNCs in the USA has been declining over the last three decades due to a decrease in the consumption of tobacco (Enomoto, Bann, Hollenbeak, & Goldenberg, 2016). Figures show that nearly 25% of HNCs that are now being diagnosed in the USA, are independent of tobacco use (de Martel et al., 2012). Between 1983 and 2004, a significant decrease in incidence has been found in sites unrelated to HPV (tongue, gum, floor of mouth, palate, other/unspecified parts of the mouth), but there was a significant increase in incidence at HPV-OSCC sites in the same time period (1973-2004) (Chaturvedi et al., 2008). The largest increase in these cancers was found in white men in their 40's or 50's.

In an analysis of 23 countries, an increasing incidence of OSCC has been found between 1983 and 2002 in men aged 60 years or younger. This trend was seen in countries including the USA, Australia, Denmark, UK, Slovakia and Canada (Chaturvedi et al., 2013). These increases were not seen in Colombia, India, the Philippines and Thailand. This may be due to differences in sexual behaviour practices which are relevant for oral HPV exposure in these developing countries (Chaturvedi et al., 2013). Figure 1.4 shows the incidence rates per 100,000 across the decades, from the 1970's to 2000.

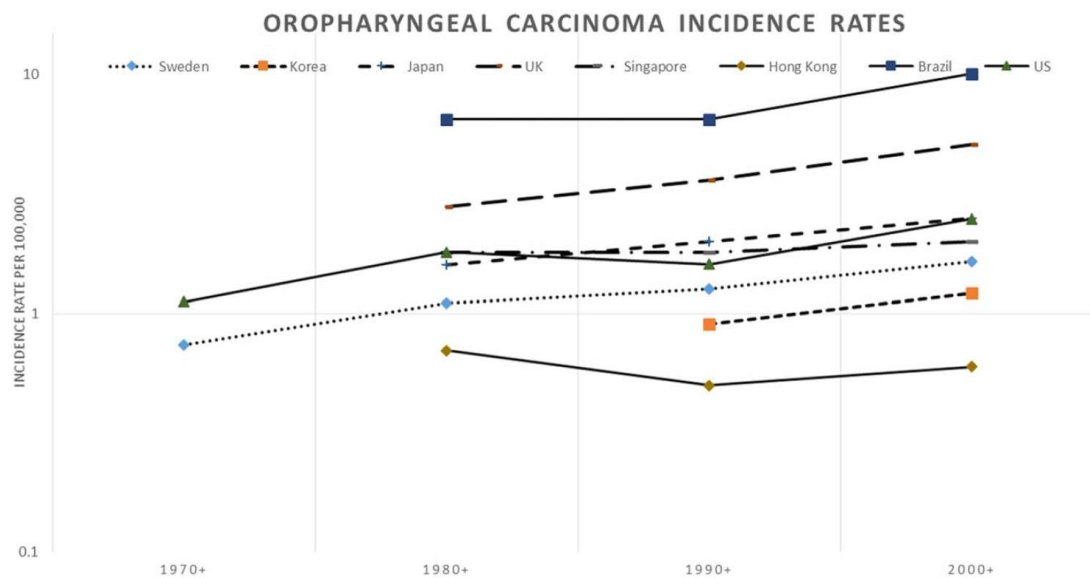


Figure 1.4: Incidence rates of OSCC in different countries by decade
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1.3.2 Incidence and prevalence of HPV-OSCC

Incidence of HPV-OSCC

Moving on to the incidence rates for HPV-OSCC, in the UK these have doubled from 1 per 100,000 to 2.3 per 100,000 in just over a decade (Mehanna, Olaleye, & Licitra, 2012). The declining incidence of HPV-negative OSCC due to decreasing rates of smoking, means that HPV-OSCC now constitutes an increasing proportion of OSCCs overall (Chaturvedi et al., 2011). Studies have shown HPV-OSCC to be prevalent worldwide and incidence rates are expected to rise (Chaturvedi et al., 2008) with numbers in the USA set to surpass the numbers of cervical cancer cases by 2020 if the current trend continues (Chaturvedi et al., 2011). It has also been projected that by 2030, half of all HNCs will be related to HPV (Chaturvedi et al., 2011).

As Figure 1.2 shows, the overall incidence of HNCs in England increased during 2002-2014. During 2002-2011, 69% of patients were males, but significant increases were found in males and females and in those aged 60 or over. Cancers of the oropharynx, base of tongue and tonsil were found to significantly increase by 47.1% in males and 37.5% in females. The HPV status of these cancers was unknown, but as a large proportion of these cancer subtypes have been found to be HPV-related, these could be HPV-associated cancers (McCarthy, Field, Rajlawat, Field, & Marcus, 2015).

Prevalence of HPV-OSCC

In Sweden, data from the cancer registry have demonstrated that the detection of HPV DNA taken from tonsillar SCC had increased from 68% from 2000-2002 to 93% in 2006-2007 (Näsman et al., 2009). Data from the USA shows the prevalence of HPV in OSCC has significantly increased from 16.3% between 1984 and 1989, to 71.7% between 2000 and 2004 (Chaturvedi et al., 2011). A meta-analysis confirmed the data from these two studies, with prevalence increasing significantly in North America and Europe. The rate of increase in Europe has been faster than in North America, increasing from 35.3% before 2000 to 73.1% in 2009 (Mehanna et al., 2013). Across all studies, the prevalence of HPV in OSCC increased from 40.5% before 2000, to 64.3% between 2000 and 2004 and 72.2% between 2005 and 2009. Worldwide it is estimated that 21,400 (25.6%) of OSCCs are attributed to HPV (de Martel et al., 2012).

A recent large systematic review of the prevalence of HPV in OSCC, accessed data from 105 articles, with data on over 9500 specimens in 23 nations. The review found a significant percentage increase of HPV-OSCC from pre-1995 to present, with this being 20.6% worldwide, 21.6% in North America and 21.5% in Europe (Stein et al., 2015).

The data presented in this section shows a substantial increase in the incidence and prevalence of HPV-OSCCs over the last 20 years, particularly in countries such as the USA, UK and Sweden. If these trends continue to increase at the current rate, the rate of HPV-OSCC could surpass that of cervical cancer by 2020.

1.4 HPV Vaccination

The HPV vaccine was approved by the Food and Drug Administration (FDA) as a primary prevention strategy against cervical cancer in 2006 and introduced into the UK in 2008, offered initially to girls. As genital HPV is sexually transmitted, it is necessary to vaccinate before sexual debut. Between 2008 and 2012, the UK administered the HPV vaccine three-dose schedule through a school-based programme for girls aged 12-13 with the bivalent vaccine (Cervarix), which prevents HPV types 16 and 18. In 2012, the school-based programme switched to the quadrivalent vaccine (Gardasil) which prevents HPV types 6, 11, 16 and 18. In the UK, since September 2014, the school-based programme implemented the two-dose schedule. The two-

dose schedule was introduced after an endorsement from the WHO in 2014 (World Health Organisation, 2014), with the recommended interval between the doses to be six months apart.

Since the approval of the HPV vaccine, a number of countries have chosen to introduce it, alongside a national vaccination programme for adolescent girls. By 2012, 19 out of the 29 countries in the EU had introduced national vaccination programmes (European Centre for Disease Prevention and Control, 2012). In Australia since 2013, the national programme additionally introduced the HPV vaccine to boys (Australian Government Department of Health, 2016) and the HPV vaccine is recommended for boys in the USA and Canada.

The HPV vaccine has also recently been approved for use in men who have sex with men (MSM) aged up to 45 (Joint Committee on Vaccination and Immunisation, 2015) and a pilot has recently been announced to offer the HPV vaccine in appointments at some Genitourinary Medicine and HIV clinics in England. The vaccine is not yet recommended by the NHS for use in school-aged boys which has caused a great deal of debate and controversy, resulting in the development of groups now campaigning for gender neutral vaccination, such as HPV Action (HPV Action, 2013).

In December 2014, the FDA approved a nonavalent (Gardasil 9) vaccine, which now covers an additional five high-risk HPV types 31, 33, 45, 52, 58. The nonavalent vaccine is currently only licensed with the three-dose schedule. These currently available vaccines are preventative and so do not help to clear already acquired infections or decrease the incidence of abnormal cytology associated with HPV (Hildesheim et al., 2016; Takes et al., 2015).

Evidence of effectiveness of the HPV vaccination

Since the introduction of the HPV vaccine, evidence has already been published demonstrating the effectiveness of the vaccine on reducing the cases of genital warts and also cases of cervical lesions (Australia Institute of Health and Welfare, 2014; Herweijer et al., 2016; Hofstetter, Ompad, Stockwell, Rosenthal, & Soren, 2016; Markowitz et al., 2013; Mesher et al., 2013; Munoz et al., 2010; Skinner et al., 2016). There is also evidence that the vaccine can provide some cross-protection to other types of HPV that are not specifically protected against in the vaccine (Skinner et al., 2016). Studies are demonstrating reductions of HPV infections in men (Bollerup et al., 2016; Giuliano et al., 2011; Goldstone et al., 2013), demonstrating

evidence of herd protection in heterosexual men (Bollerup et al., 2016) and efficacy of the HPV vaccine in both heterosexual and MSM men (Giuliano et al., 2011; Goldstone et al., 2013).

Vaccination against oral HPV infection

Vaccine efficacy against oral HPV infection and OSCC has not been fully evaluated. A study conducted as part of the Costa Rica HPV vaccine trial measured oral HPV prevalence in women and found oral HPV16/18 to have a lower prevalence in vaccinated women (1/2910) than those in the placebo (hepatitis A vaccine) group (15/2924), but the number of infections found in either group were small and this was only measured at one time point, 4 years after vaccination (Herrero et al., 2013).

These studies suggest that there is some evidence supporting the possibility that the HPV vaccine may prove to be effective in reducing the incidence of oral HPV, the effects of which will not be seen for years to come due to the higher average age demonstrated in OSCC compared to cervical cancer (Gillison et al., 2013). As the majority of HPV-related OSCC cases are caused by HPV16 and HPV18, which are high-risk HPV types included in both the Cervarix and Gardasil vaccines, it is reasonable to expect that these vaccines might be able to also prevent oral HPV16/18 infection (Takes et al., 2015). Clinical trials evaluating the efficacy of HPV vaccines for the prevention of oral HPV infection are difficult to carry out as there is a lack of data regarding rates of incidence and clearance of oral HPV infection (Gillison et al., 2013).

1.5 Survival rates of HPV-related HNC worldwide and the UK

The majority of HNCs are referred to a specialist by GPs (Health and Social Care Information Centre, 2013); however general dental practitioners also have an important role to play. As yet, no effective screening programme exists to detect HPV-OSCC. This is because there is not yet the ability to detect precancerous lesions or subclinical/early-stage HNCs (Gillison, Chaturvedi, Anderson, & Fakhry, 2015). It is also important to remember that there is no established intervention for reducing cancer incidence, cancer mortality or screening for HNC. Early diagnosis is crucial in HNC and stage I or II disease have much better two year survival rates compared to those diagnosed at advanced stages III and IV (Rusthoven et al., 2010). After exploring screening strategies with the equivalent of a 'Pap-test' for the oropharynx, authors

concluded it may not be feasible due to limitations in sampling (Fakhry, Rosenthal, Clark, & Gillison, 2011).

Survival rates for HPV-positive patients compared to HPV-negative patients are considerably improved, with the median survival of HPV-positive patients being almost 4 years, compared to less than 3 years for HPV-negative patients (Gillison et al., 2000). The 3 year overall survival rate in HPV-positive patients was shown to be 82.4% compared with 57.1% in HPV-negative patients (Ang et al., 2010). Five year survival rates in the same groups range from 75-80% in HPV-positive patients compared with 45-50% in HPV-negative patients (Ang et al., 2010). In a prospective analysis of patients with stage III or IV OSCC, patients with an HPV-positive tumour status had higher overall-survival and progression free survival at 2 years compared to HPV-negative patients (Fakhry et al., 2008). The effects of HPV-positive tumour status still remained independently associated with a reduced mortality risk after controlling for age, tumour stage and comorbidities.

In a sample of over 500 OSCC patients in a USA study, 5 year survival was found to be better in patients with HPV16 than other HPV types and those who were HPV-negative (Goodman et al., 2015).

Figure 1.5 shows the results from a retrospective analysis which divided patients with stage III and stage IV OSCC into risk of death categories (Ang et al., 2010). The groups were classified as:

- Low risk (93% 3 year survival)
 - HPV+, smoked less than 10 pack years
 - HPV+, smoked more than 10 pack years, diagnosed at low clinical staging (N0-N2a)
- Intermediate risk (70.8% 3 year survival)
 - HPV+, smoked more than 10 pack years, diagnosed at intermediate clinical staging (N2b-N3)
 - HPV-, smoked less than 10 pack years, diagnosed at intermediate tumour stage
- High risk (46.2% 3 year survival)
 - HPV- and either T4 or >10 year pack history

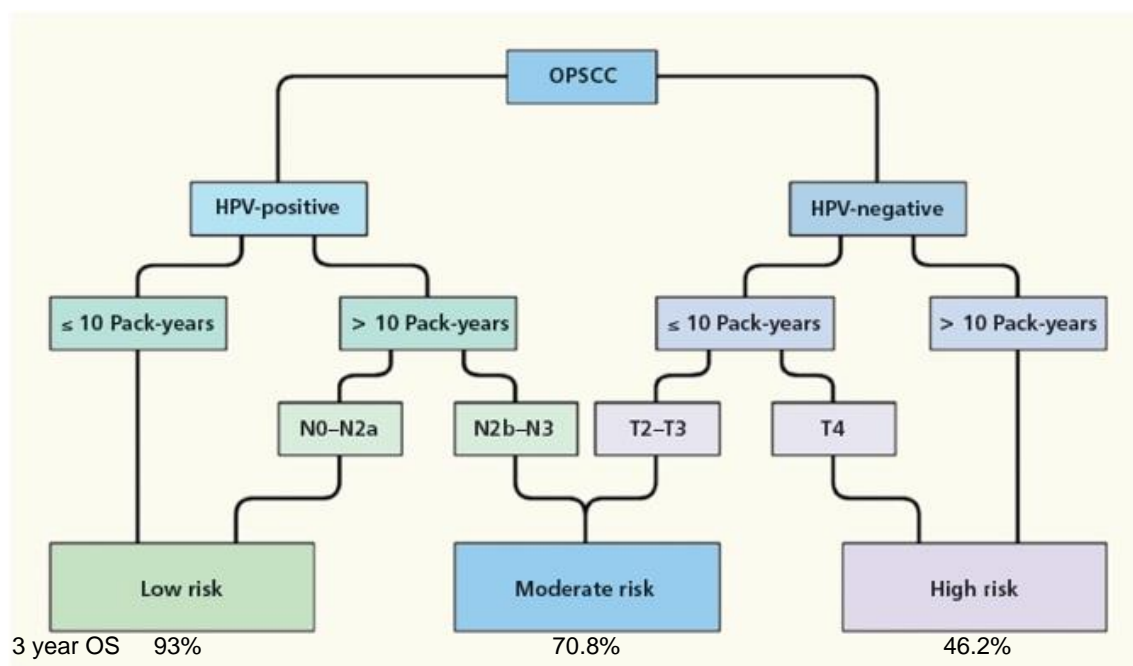


Figure 1.5: Risk stratification for OSCC

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Survival and treatment

When comparing survival in HPV-positive and HPV-negative OSCC by treatment, significantly worse outcomes were found for HPV-negative patients when they were treated with primary radiation compared with primary surgery (Wang, Liu, Gornbein, & Nguyen, 2015). No differences were found for HPV-positive patients between primary radiation and primary surgery.

Looking at survival in patients with nonmetastatic OSCC treated with radiotherapy between 2000 and 2010, lower 5 year overall survival was found in patients with a higher TNM stage who were also HPV-negative, but this was not the case for HPV-positive patients (Huang et al., 2015). Five year survival dropped from 70% for stage I to 30% in stage IV for HPV-negative patients, but the decrease was not so drastic in the HPV-positive patients (stage I 88%, stage IV 74%).

Although HPV-OSCC patients have a favourable response to treatment, up to 30% experience recurrence (Guo et al., 2015) and the majority of recurrences occur within a year for both p16 positive and p16 negative patients (Fakhry, Zhang, et al., 2014). HPV-OSCC patients have lower recurrence rates than their HPV-negative counterparts, but they have a higher proportion of recurrences that occur at distant sites and nontraditional sites, such as the kidney, brain and

skin (Huang et al., 2013; Müller et al., 2012). HPV-OSCC patients are also less likely to develop second primaries than their HPV-negative counterparts.

There is a substantial amount of evidence to show that the survival rates for HPV-OSCC patients are more favourable than non-HPV related HNCs. This has both clinical and psychological implications which are discussed further in this thesis.

1.6 Implications for treatment of HPV-related HNC

HPV testing has been introduced as a clinical standard of care in OSCC in the USA, under the National Comprehensive Cancer Network (NCCN) guidelines (Pfister et al., 2012).

Recommendations for HPV testing methods are variable, with the NCCN recommending using PCR or ISH and the College of American Pathologists recommend using ISH and/or detection of p16 IHC (see section 1.2.2). Testing tumours for HPV is also taking place in some UK centres as part of the diagnostic and treatment planning process (Roe, Drinnan, Carding, Harrington, & Nutting, 2014), and the National Institute for Health and Care Excellence (NICE) published recommendations in February 2016 to use p16 IHC for testing OSCC, but that it should only be regarded as positive if ‘there is strong nuclear and cytoplasmic staining in more than 70% of tumour cells’ (National Institute for Care and Excellence, 2016, section 1.5). The guidelines also recommend confirming HPV status using HPV DNA or ISH, but does not recommend de-intensifying treatment in HPV-positive patients. Although there is evidence that prognosis differs with HPV status, this has not yet been integrated into the staging classification (Gillison et al., 2000).

The treatment for patients diagnosed with HPV-OSCC is currently the same as those with HPV-negative OSCC. If patients are diagnosed at an early stage and their cancer is clinically confined to the oropharynx, surgical resection may be sufficient. Primary radiation is considered to be equivalent to surgery for these early stage cancers. If primary tumours are large or have regional nodal metastases, chemoradiation is frequently selected as treatment for OSCC. Surgical resection followed by adjuvant chemoradiation is also an option, as well as induction chemotherapy followed by chemoradiation (Posner et al., 2007).

In the UK, most patients with HPV-OSCC present at an advanced stage (stage III and IV) and undergo multimodality treatment. This can include surgery and/or radiotherapy and/or

chemotherapy. Some patients receive triple-modality treatment, but single-modality therapy is recommended to be provided if possible to minimise toxicity (Roland & Paleri, 2011). Treatment can be associated with morbidity and occasional mortality (Bonner et al., 2010; Curran et al., 2007). As patients diagnosed with HPV-OSCC have a much improved prognosis compared to their HPV-negative counterparts due to its responsiveness to treatment (Argiris et al., 2014; Ragin & Taioli, 2007), research is underway to explore ways to limit toxicity related to treatment and de-escalate treatment for patients with HPV-positive disease (Mehanna et al., 2012). This is being explored by reducing the number of treatment modalities and/or reducing intensity/dose of a given modality without compromising efficacy (Mirghani et al., 2015). Results from these trials will be expected in the next few years. In a study investigating oropharyngeal cancer patients' preferences for receiving less invasive treatment, Brotherston and colleagues found that patients valued survival over quality of life (Brotherston et al., 2013).

Many studies are underway to define de-escalation more precisely. As HPV-OSCC patients tend to be younger, it is important to also consider the long-term implications of treatment and whether this can be modified. Appendix 1.1 shows the current ongoing trials investigating the feasibility of deintensifying the treatment offered to HPV-OSCC patients. These trials include: radiation alone in risk-stratified OPSCC; decreased dose of radiation; substitution of cetuximab for cisplatin; and surgical resection followed by reduction/elimination of chemotherapy or radiation therapy (Roland & Paleri, 2011).

1.7 Summary

This chapter has provided the epidemiological context for this thesis. HNC affects over 11,000 men and women in the UK each year. An increasing number of these are OSCC caused by HPV; most commonly HPV16. This field is still in relative infancy and there are still a large number of unknowns regarding the progression of oral HPV to cancer as the natural history is not well understood. Although research from cervical cancer can be useful, key differences in incidence and prevalence have been established between cervical HPV and oral HPV. Patients diagnosed with HPV-OSCC tend to be younger, non-smokers and non-drinkers compared to those diagnosed due to the main risk factors of smoking and alcohol. Sexual behaviour has been strongly associated as a risk factor for the acquisition of oral HPV. There is hope that the HPV vaccine which is currently offered to girls in the UK when they are in year 8 at school could

also have an impact on oral HPV, however the effects of this will not be seen for another 45 years. HPV-OSCC does appear to respond better to treatment than HPV-negative cancers and survival rates are much more favourable. This has led to a number of clinical trials investigating the possibility of offering patients with HPV-OSCC less intensive treatment, considering the long-term implications of current treatments on what are now younger patients. Chapter 2 provides background into the psychosocial factors associated with HNCs and how health psychologists can use these findings to explore how patients diagnosed with HPV-OSCC may be impacted.

CHAPTER 2. PSYCHOSOCIAL ISSUES RELATED TO HEAD AND NECK CANCERS

The focus of this thesis is examining the psychosocial impact of human papillomavirus- oropharyngeal squamous cell carcinoma (HPV-OSCC), therefore it is important to review the literature about the psychosocial impact of head and neck cancer (HNC) more generally and to consider the implications this has on the partner or caregiver of the patient. In this chapter I discuss the existing evidence exploring the psychosocial impact of HNC, including psychological distress, quality of life (QOL), disfigurement and dysfunction.

2.1 Psychosocial impact of head and neck cancers¹

Cancer is often perceived as ‘a death sentence’ (Moser et al., 2014) with a recent general population study across the USA, Germany, France, Italy, Japan and the UK, showing 66% to indicate ‘death as a result of cancer’ as a great concern should they be diagnosed with cancer (Ramers-Verhoeven, Geipel, & Howie, 2013). A wealth of literature has found cancer to have a significant psychological impact on patients (Stanton, 2006) and the prevalence of clinically significant depression in cancer patients is greater than the general population (van’t Spijker, Trijsburg, & Duivenvoorden, 1997). A growing number of those diagnosed with cancer are surviving beyond 5 years and it is important to understand the psychosocial impact of diagnosis and treatment. Overall access to psychological services by cancer patients has been found to be low (Waller, Williams, Groff, Bultz, & Carlson, 2013).

It has long been recognised that a diagnosis of HNC is associated with psychosocial distress. The term psychological distress encompasses depression, anxiety, and symptoms of acute stress (Shiraz, Rahtz, Bhui, Hutchison, & Korszun, 2014). A diagnosis of HNC is often described as highly traumatic (De Boer, McCormick, Pruyn, Ryckman, & van den Borne, 1999) due to disfigurement and loss of essential functions such as eating, speaking and breathing (Duffy et al., 2007). Patients have been shown to isolate themselves from their friends and family due to

¹ The focus of this thesis is HPV-OSCC, but as this chapter is discussing the psychosocial issues related to head and neck cancer (HNC) more generally, the term HNC will be used in this chapter.

their appearance (Dhooper, 1985) and nearly 60% have said they have felt stigmatised or discounted because of their appearance (Strauss, 1989). Challenges and concerns associated with a diagnosis of HNC include changes to appearance, eating and drinking, communication, challenges to employment and finances, sexuality and coping (Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha, 1996; Penner, 2009). Challenges for family caregivers are also recognised (Penner, 2009), and one study found problem domains identified by HNC patients to be communicating with the partner, functioning in the family, and social and interpersonal relations (Rapoport, Kreitler, Chaitchik, Algor, & Weissler, 1993). Compared with laryngeal cancer patients, oral cancer patients had significantly more concerns about current illness, subjective evaluation of health, eating and chewing, social interactions, pain, and disfigurement (Chaturvedi et al., 1996).

Body image is a key factor when considering the psychosocial impact of HNC. Figure 2.1 illustrates a conceptual framework of body image in HNC patients developed on the basis of a review of the literature (Rhoten, Murphy, & Ridner, 2013). The framework proposes that diagnosis and treatment for HNC results in two main physical effects of disfigurement and dysfunction. The framework suggests that patients may have dysfunction and/or disfigurement at any time during their diagnosis and treatment pathway, the effect of which may be moderated by personal, social and environmental factors. The framework also acknowledges psychological and social outcomes, including QOL. This framework will structure my overview of the evidence of psychological outcomes, QOL and social outcomes and how these relate to disfigurement and dysfunction.

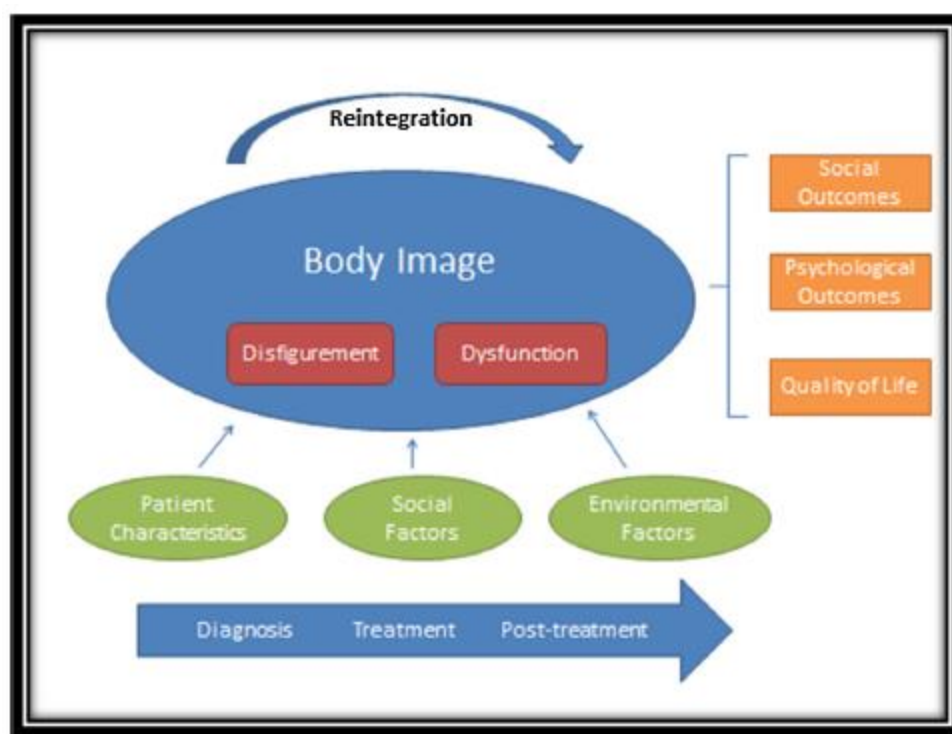


Figure 2.1: A conceptual framework of body image in head and neck cancer patients
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2.1.1 Psychological outcomes

Studies measuring anxiety and depression in this patient population have used validated clinical tools, including the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) and the mood and anxiety subscales of the validated University of Washington Quality of Life (UWQOL) measure (Hassan & Weymuller, 1993). The literature exploring the psychosocial impact of HNC on patients has yielded mixed results for anxiety, depression and QOL, but as a variety of measures are used to assess these psychological domains, it is difficult to compare findings across studies or conduct meta-analyses.

Prevalence of psychological distress and patterns over time

Table 2.1 summarises selected previous research with HNC patients that has reported anxiety and depression measured using the HADS and the UWQOL, so results can be compared with studies using the same measures. Levels of anxiety range from 16-22% (Hassanein, Musgrove, & Bradbury, 2005; Hutton & Williams, 2001; Kanatas, Ghazali, Lowe, & Rogers, 2012; Neilson et al., 2013) and levels of depression range from 5% reporting extreme depression one year post-treatment (Chen et al., 2013), to 29% being above the clinical threshold for depression 3 weeks post-treatment (Neilson et al., 2013). A UK-based study showed elevated levels of

depression and anxiety in both men and women compared to other studies with HNC patients (Shiraz et al., 2014). This may in part be due to their sample including 25% Asian cancer patients, who have been shown to have a more fatalistic attitude than patients from white British backgrounds (Roy et al., 2005). Longitudinal studies presented in Table 2.1 show levels of depression to change with time since diagnosis, with one study finding levels of depression at their highest 3 weeks post-treatment and levels of anxiety to be greatest 18 months post-treatment (Neilson et al., 2013). Trends have also shown depression to decrease with time since illness onset and to be slightly less common among patients attending a support group (Hutton & Williams, 2001). A study measuring psychological distress in HNC patients 7-11 years after they had received curative treatment found levels of psychological distress was higher than anticipated (Bjordal & Kaasa, 1995), but as patients were no longer involved in the hospital system and receiving follow-up appointments, they were no longer being offered any systemic support or psychological treatment.

Other studies using the HADS have shown depression to be higher than the UK norms for the general population, with anxiety being similar to UK norms for the general population (Clarke, Newell, Thompson, Harcourt, & Lindenmeyer, 2013) and 25% of HNC patients to have clinically significant distress levels (Henry et al., 2014). Depression, distress and anxiety have been found to be greatest in younger patients (Hutton & Williams, 2001; Kanatas et al., 2012; Neilson et al., 2013)

Table 2.1: Examples of studies reporting anxiety and depression in head and neck cancer patients using the HADS and UWQOL

Reference	Sample	Outcome measures	Scoring above clinical threshold		Findings
			Anxiety	Depression	
Hutton and Williams, 2001 UK	18 HNC patients being actively treated	HADS (scores ≥ 8 =clinical threshold)	22%	22%	<ul style="list-style-type: none"> • Age significantly predicted distress and depression, but not anxiety or low self-esteem • Age did not predict clinically relevant anxiety or depression, but there was a trend for it to predict clinically important distress • Time since onset of illness was significantly associated with lessening of depression • Neither sex nor recurrence of illness was significantly associated with distress, anxiety, or depression
Hassanein et al., 2005 UK	68 HNC patients who had received treatment for oral cancer between October 1992 and October 1997	HADS UWQOL EORTC QLQ-30 Mental adjustment to cancer scale	16%	19%	<ul style="list-style-type: none"> • No significant differences between age, sex, site, stage and treatment modalities of the tumour • A strong negative association was found between anxiety and depression and poor head and neck specific functional measures • A strong positive association between ineffective coping strategies and anxiety and depression

HADS=Hospital Anxiety and Depression Scale; UWQOL=University of Washington Quality of Life; EORTC QLQ-30=European Organisation for Research and Treatment of Cancer; PCI=Patient Concerns Inventory

Table 2.1: Examples of studies reporting anxiety and depression in head and neck cancer patients using the HADS and UWQOL (contd.)

Reference	Sample	Outcome measures	Scoring above clinical threshold		Findings
			Anxiety	Depression	
Kanatas et al., 2012 UK	204 HNC patients if disease-free and under routine follow-up at least 6 weeks after completing treatment	UWQOL PCI	20% on UWQOL 10% raised anxiety on PCI	17% on UWQOL 10% raised mood on PCI 10% raised depression on PCI	<ul style="list-style-type: none"> More significant problems of anxiety and/or mood were reported on the UWQOL by younger patients
Chen et al., 2013 USA	211 HNSCC patients previously treated with radiotherapy and disease-free with at least 1 year of follow-up; cross-sectional; 120 at 3 years; 54 at 5 years	UWQOL (mood score of ≤ 25 to indicate incidence of depression)		Somewhat depressed 12% (1 year), 8% (3 years), 9% (5 years) Extremely depressed 5% (1 year), 7% (3 years), 4% (5 years)	<ul style="list-style-type: none"> Only a small number were receiving medication in the form of antidepressants, or actively undergoing or seeking psychiatric care

HADS=Hospital Anxiety and Depression Scale; UWQOL=University of Washington Quality of Life; EORTC QLQ-30=European Organisation for Research and Treatment of Cancer; PCI=Patient Concerns Inventory

Table 2.1: Examples of studies reporting anxiety and depression in head and neck cancer patients using the HADS and UWQOL (contd.)

Reference	Sample	Outcome measures	Scoring above clinical threshold		Findings
			Anxiety	Depression	
Neilson et al., 2013 Australia	101 first time HNC patients treated with radiotherapy with curative intent 75 completed 3 week post-treatment 37 completed 18 month post-treatment	HADS (scores ≥ 8 =clinical threshold)	20% Pre-treatment 17% 3 weeks post-treatment 22% 18 months post-treatment	15% Pre-treatment 29% 3 weeks post-treatment 8% 18 months post-treatment	<ul style="list-style-type: none"> The severity of physical symptoms associated with HNC tumours and treatment was a significant predictor of anxiety and depression scores (more physical symptoms associated with higher anxiety and depression scores) Age of participants predicted anxiety and were higher in younger participants
Shiraz et al., 2014 UK	124 HNC patients from outpatient HNC clinics	HADS (scores ≥ 8 =clinical threshold) Acute Stress Disorder Scale (ASD)	48% women 42% men	35% women 38% men	<ul style="list-style-type: none"> Acute stress was found in 8% of men and 33% of women

HADS=Hospital Anxiety and Depression Scale; UWQOL=University of Washington Quality of Life; EORTC QLQ-30=European Organisation for Research and Treatment of Cancer; PCI=Patient Concerns Inventory

Predictors of psychological distress

A study looking at the predictors of psychological distress in HNC patients found when comparing this patient population to patients with other cancers, HNC patients were frequently more distressed on more than one occasion post diagnosis (Singer et al., 2012). Patients undergoing surgery appear to report greater psychosocial impact when compared with alternative methods of treatment, as alternative treatments such as radiotherapy are associated with better functional outcomes (e.g. understandability of speech) (Allal, Nicoucar, Mach, & Dulguerov, 2003; De Boer et al., 1995; Taylor et al., 2004). A review of studies reporting patient-reported outcomes in HNC found depression associated with loss of self-esteem, and a modified individual and social identity (Babin et al., 2008).

Studies have presented findings on the support and information needs of HNC patients and found moderate to high levels of supportive care needs in the 6 months from the start of treatment (Chen et al., 2012). Highest information needs in patients occurred at the pretreatment stage, but the greatest overall and individual care needs occurred 2 months after starting radiotherapy or chemoradiotherapy. Supportive care needs were found to be higher in those without religious beliefs, those with a high educational level, high functional level, high overall physical symptom severity, and high baseline anxiety. Higher physical and daily living needs were significantly related to individual symptoms (Chen et al., 2012) and worsening physical symptoms have an adverse effect on psychosocial distress of patients (Badr, Gupta, Sikora, & Posner, 2014). Sixty-eight per cent of all patients in a cross-sectional survey reported they had unmet needs; the highest unmet needs being psychological (Henry et al., 2014).

Maladaptive coping strategies of helplessness and fatalism were adopted by patients (Chaturvedi et al., 1996). Maladaptive coping strategies such as helplessness/hopelessness, anxious preoccupation and fatalism have been shown to be strongly associated with anxiety and depression (Hassanein et al., 2005). Qualitative work has found patients to describe a feeling of hopelessness and the loss of meaning in life in the context of their illness, feeling like they were fighting an endless battle (Moore, Chamberlain, & Khuri, 2004). Beliefs about how chronic the disease is has been shown to predict depression after treatment (Llewellyn, McGurk, & Weinman, 2007). Specifically looking at the relationship between anxiety, depression and coping strategies adopted by HNC patients, 6-12 months after their diagnosis, patients with

higher levels of anxiety and depression used 'blame self', 'wishful thinking' and 'avoidance' coping strategies (Elani & Allison, 2011). Conversely, benefit finding in HNC patients has also been reported, with moderate to high levels found in these patients (Harrington, McGurk, & Llewellyn, 2008). Benefit finding was independently positively associated with optimism and positive reappraisal.

Examining patient's ratings of disfigurement against psychosocial outcomes in HNC (Katz, Irish, Devins, Rodin, & Gullane, 2003) found women reported more depressive symptoms than men. Those reporting more depressive symptoms rated themselves as more disfigured, and individuals with social support reported higher psychological well-being. Social support was found to moderate disfigurement and psychological well-being in women but not men. Patients not returning to work after surgery have been found to find it more difficult to adapt psychologically (Terrell, Nanavati, Esclamado, Bradford, & Wolf, 1999).

A study exploring the psychological impact of facial disfigurement on both HNC patients and their partners found scores on the HADS to be within normal range for patients and within normal range for depression in partners (Vickery, Latchford, Hewison, Bellew, & Feber, 2003). Partners had higher median scores for anxiety and these were classified as borderline clinical, demonstrating the experiences of illness and treatment are clearly different for partners. This group of patients did not have greater levels of psychological distress compared to other cancer patients. The degree of facial disfigurement has been found to be positively related to psychological distress and distress in reaction to unpleasant behaviour of others when patients did not feel confident in social interactions (Hagedoorn & Molleman, 2006).

Another factor which could cause psychological distress in HNC patients is sexual function, also known in the literature as sexuality. A recent review about sexuality and HNC (Rhoten, 2016) found nine studies eligible for inclusion in the review, five of these with the specific aim to examine sexuality in patients with HNC (Low et al., 2009; Moreno et al., 2012; O'Brien, Roe, Low, Deyn, & Rogers, 2012; Rogers, Hazeldine, O'Brien, Lowe, & Roe, 2014; Singer et al., 2008). The prevalence of HNC having a negative impact on sexual function ranged from 24% to 100%, with 50% of that 100% reporting it to be an extremely negative impact (Moreno et al., 2012). Two studies included in the review investigated the relationship between sexual function and QOL and found impaired sexual function was negatively associated with QOL (Psoter,

Aguilar, Levy, Baek, & Morse, 2012; Zwahlen et al., 2008). Issues with sexual relationships following treatment for HNC have also been reported by both patients and their partners (Low et al., 2009; Manne, Badr, & Kashy, 2012). Substantial problems were reported for sexual interest and enjoyment by one-third of respondents overall, and one-quarter for problems with intimacy that causes them some concern (Low et al., 2009). Problems with intimacy declined with age, from 36% in under 55 year olds, to only 6% in those aged 75 years or older.

Fear of recurrence in HNC patients is another factor which could have a negative impact on the patient's psychological health. Studies in this patient population have found the prevalence of significant fear of recurrence in a group of nearly 200 post-treatment HNC patients to be 35% and this remained stable over time (Ghazali et al., 2013). Being under 65 years of age, reporting anxiety and mood related problems as well as self-reporting fear of recurrence, were all predictors of having significant fear of recurrence. When looking at assessing fear of recurrence using the Patient Concern Inventory or the Fear of Recurrence questionnaire, fear of recurrence was selected as an issue by 42% of patients (Rogers, Scott, Lowe, Ozakinci, & Humphris, 2010). It was not possible to predict which patients would report fear of recurrence by their clinical characteristics.

Summary

The research presented illustrates that there are a number of factors that contribute to HNC patients' psychosocial distress with the most frequently measured outcomes being anxiety and depression. Understandably HNC patients exhibit higher levels of depression just after starting treatment as disabilities that arise from treatment for HNC have been described by patients as worse than the cancer itself (Burns, Chase, & Goodwin, 1987; Gamba et al., 1992). It is also evident that anxiety is more prevalent in younger cancer patients and those with more symptoms. It is important to note that psychological distress and QOL are not independent of each other (Bornbaum et al., 2012; de Graeff et al., 2000; Hammerlid et al., 1997). Psychological distress also interacts with disfigurement, dysfunction, coping, social support and sexual functioning in HNC patients.

2.1.2 Quality of life

Although QOL is a widely used concept, it lacks a clear definition due to the different ways in which the term can be used. In the context of the health literature, health-related QOL (HRQOL) assesses physical, psychological and social domains (Llewellyn, McGurk, & Weinman, 2005) and QOL is defined by the Centers for Disease Control and Prevention as 'a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life' (Centers for Disease Control and Prevention, 2016). In the health literature, QOL is commonly used as a psychological concept or as a medical outcome (Rejeski & Mihalko, 2001) and HRQOL has been stated to be important in Oncology because a patients' well-being is substantially impacted by the disease and treatment (Secord et al., 2015). As previously stated, QOL is not independent from psychological distress and psychological distress can often predict QOL. Common general measures of QOL within the HNC population are the UWQOL and the European Organisation for Research and Treatment of Cancer QLQ (EORTC QLQ) (Aaronson et al., 1993), with a HNC specific version EORTC QLQ-H&N35 (Bjorndal et al., 2000). Specific HNC QOL measures have now been developed to include questions regarding some of the functional changes such as swallowing/eating and speaking/communication.

Predictors of QOL

QOL is commonly measured in HNC patients and has been the focus of some reviews (Dunne et al., 2016; Llewellyn et al., 2005; Moore, Ford, & Farah, 2014; Rogers, Ahad, & Murphy, 2007). One review found the psychosocial variables of personality, social support, depressive symptoms, and satisfaction with consultation and information were associated with HRQOL, as well as behavioural factors such as consumption of alcohol and tobacco (Llewellyn et al., 2005). The support needs of patients in relation to QOL have also been reviewed and found these variables to relate to coping with both the psychosocial and physical aspects of radiotherapy (Moore et al., 2014). Aspects shown to cause a significant impact on QOL included depression, anxiety and malnutrition. The most recent review examined the evidence of associations between psychological factors and QOL (Dunne et al., 2016). The psychological variables more often measured were depression, anxiety and distress, and were found to have negative associations with QOL outcomes. Other psychological factors found to have associations with

QOL included coping, neuroticism and fear of recurrence. There are difficulties associated with measuring QOL, which include its lack of clear definition and lack of consistency in its measurement.

Leventhal's Common-Sense Model (CSM) proposes that patients' representations of their illness guide coping mechanisms and outcomes such as QOL (see section 3.4.1.1) (Leventhal, Meyer, & Nerenz, 1980). In a study investigating the utility of this model as a framework for determining changes in outcomes over time, baseline illness and treatment beliefs were not predictive of HRQOL, individualised QOL, or anxiety 6-8 months after treatment (Llewellyn et al., 2007). The five dimensions of the CSM were found to be related to coping. The strongest relationship with identity was the use of venting and self-distraction, with the use of more coping strategies at 6-8 months; longer timeline beliefs were most strongly associated with planning and active coping at 6-8 months; stronger beliefs about consequences were associated with denial, venting and planning in the short-term, and self-distraction, denial and venting implemented at 6-8 months; stronger treatment concerns were associated with increasing levels of denial; and stronger emotional representations were most strongly associated with substance use, denial, self-distraction and planning.

HNC patients were interviewed in a small qualitative study and their support needs were explored (Moore, Ford, & Farah, 2014). Patients were asked to describe their current QOL and their support needs post-treatment. In the first six to twelve months following treatment, QOL was affected by psychological distress such as depression and anxiety. Feelings of isolation were described following the loss of support from the hospital after treatment had finished. Support was sought from professional and personal networks during and after treatment and coping strategies were disrupted when patients were away from the hospital environment as they felt a loss of supportive care.

In long-term survivors of HNC, objective measures of word intelligibility measured using the 'Assessment of Intelligibility of Dysarthric Speech' (Yorkston & Beukelman, 1981) have been found to be significantly associated with factors affecting survivors QOL, such as enjoyment of recreation, perception of chewing and swallowing, willingness to eat in public and reported normalcy of diet (Meyer et al., 2004). Another study exploring the psychological impact of facial disfigurement in HNC patients found that although their QOL was lower than the general

population, it was comparable with other HNC samples (Vickery et al., 2003). Other research using the EORTC QLQC-30 showed overall global QOL in HNC patients to be satisfactory (Chaukar et al., 2009).

Scores for QOL has been shown to be significantly better in patients diagnosed at an early stage and treated with surgery alone, compared with patients diagnosed at an advanced stage and given either radiation alone or multimodality treatment (Chaukar et al., 2009).

Sociodemographic correlates with QOL

A review of 35 articles provides an overview of sociodemographic predictors of QOL in HNC patients, as well as the functional and psychological outcomes associated with HNC (Babin et al., 2008). Being married, employed, having higher educational levels (Duffy et al., 2002) and no comorbidities (Fang et al., 2002), all tend to be associated with better QOL. Poorer ratings of QOL are found in younger patients. Patients from a lower socioeconomic position appear to present at a more advanced stage and have an increased number of disabilities associated with late stage diagnosis, having a significant effect on HRQOL. As these patients were also more likely to have jobs where physical strength was required, they were less inclined to attend rehabilitation as they did not want to accept change from the consequences of their treatment (Babin et al., 2008). This resulted in patients becoming disabled and unable to work, resulting in reduced QOL.

Patterns of QOL over time

QOL has been shown to be reduced even years after treatment (Meyer et al., 2004). The most significant changes in QOL in HNC survivors occur within the first year since diagnosis, with a lower QOL at one year post diagnosis being associated with a significantly increased risk of death (Mehanna & Morton, 2006). A study measuring QOL in HNC patients longitudinally at three, 12 and 24 months (Morton, 2003) found global QOL improved with time and patients coped well.

Summary

The findings from these research studies show there are a multitude of factors associated with QOL, with depression and anxiety being shown to be negatively associated with QOL. There

are also patient factors which can result in improved QOL, such as being married, employed and having a higher level of education. Younger patients were found to have lower QOL, as well as those who received multimodality treatment rather than single modality treatment. Support needs have also been shown to be influential in both QOL and psychological distress. QOL is related to function in HNC patients, with concerns around speech, chewing and swallowing affecting QOL. It is important to identify these factors, as alleviating them through medical, social or psychological interventions could result in HNC patients experiencing improved QOL.

2.1.3 Social outcomes

Social outcomes include those which affect the patient in the social context, such as social isolation and avoidance, shame and stigma, effects on relationships, and work. Social support has the potential to mitigate adverse social outcomes. Psychological distress has been found to be more common in HNC patients compared to other cancer patients, which might be due to their perception of less social support despite not asking for support from professionals (Singer et al., 2012). Having social support in the form of fellow patients during radiation was found to lead to less loneliness, reduction of uncertainty and reduced negative feelings (Egestad, 2013) and an increased feeling of control and self-esteem. It was also recognised that contact with fellow patients could lead to psychological distress, due to the emotions attached to being with someone who was seriously ill and sick from their treatment. In addition, patients sympathised with each other and therefore were effected when something happened to one of their fellow patients (Egestad, 2013). Social support has been found to be associated with fewer negative psychological symptoms and greater well-being in HNC patients (Bowers, 2008). A more recent study conducted in Japan confirmed this, finding patients who live with their family scored lower on the HADS than those who did not. Social distress, in this study defined as how much distress patients felt about their appearance following their surgery, was significantly positively associated with psychological distress and negatively associated with social support and self-efficacy (Deno et al., 2012). Social support from friends was found to be positively influential on psychological distress, and social support from the family was not found to significantly influence social or psychological distress.

Changes in communication are a key challenge associated with HNC following treatment (Chaturvedi et al., 1996; Penner, 2009; Rapoport et al., 1993). Qualitative studies with HNC

survivors have found communication to be a common theme emerging from the data (Lang, France, Williams, Humphris, & Wells, 2013; Parker et al., 2013; Swore Fletcher, Cohen, Schumacher, & Lydiatt, 2012). “Changes in communication” (Swore Fletcher et al., 2012), “living with the aftermath” (Parker et al., 2013) and “disruption to daily life” (Lang et al., 2013) were all themes reflecting the effect of treatment on communication which could result in patients feeling isolated, experiencing difficulties talking in groups, living with a persistent disability and also challenges to their confidence and self-esteem. The importance of social support was also reflected in these studies through “going deeper into life” (Swore Fletcher et al., 2012), “being supported” (Parker et al., 2013) and “sharing the burden” (Lang et al., 2013). Patients felt that it was important to be supported and that they would not have been able to do it alone, but some also reported feeling like they had become a burden (Parker et al., 2013). Social, recreational and sexual functioning have also all been shown to be negatively affected (De Boer et al., 1999). These interviews were conducted with a small number of patients who ranged from 7 months to 26 months after surgery, so there is the possibility that these themes may not be pertinent to HNC patients at all time points after their surgery. However, themes developed in a meta-synthesis reflected similar themes, and this included studies at various time points from pre-diagnosis to beyond treatment (Lang et al., 2013).

Summary

Common factors found to affect social outcomes of HNC patients included the amount of support they receive and problems with communication. Social support has been found to be associated with less psychological distress and greater well-being, yet some patients say they feel isolated and that they also do not want to be a burden. Having social support from fellow patients has been shown to reduce patients’ feelings of loneliness, but problems with communication can lead to patients isolating themselves due to having functional difficulties talking in groups and psychological difficulties with a lack of confidence and self-esteem.

2.1.4 Disfigurement and dysfunction

Disfigurement

The term disfigurement is used to describe ‘visible and negative alteration in appearance caused by disruption of skin, soft tissue, or bony structures’ (Katz, Irish, Devins, Rodin, &

Gullane, 2000, p136). Facial disfigurement, whether this be from the cancer itself or following surgery, has been considered the most stressful aspect of HNC (Koster & Bergsma, 1990; van Doorne, van Waas, & Bergsma, 1994). In 1983, Dropkin and colleagues developed the 'Dropkin Disfigurement and Dysfunction Scale' to measure the severity of visible disfigurement and dysfunction after surgery for HNC (Dropkin, Malgady, Scott, Oberst, & Strong, 1983). In a study of 117 HNC patients who were about to undergo disfigurative surgery, the relationship between coping with surgical disfigurement/dysfunction and length of hospital stay was investigated. Coping effectiveness was diminished in these patients and the degree of surgical deficit ranged from mild to severe disfigurement and dysfunction. If patients were coping effectively before the surgery, this predicted post-surgery coping behaviour. In a cohort study of 75 of these patients, anxiety levels before surgery were extremely high (Dropkin, 1999).

More recently, Katz and colleagues developed an observer-rated disfigurement scale with a single item to measure the degree of disfigurement on a nine-point likert scale (Katz et al., 2000). Patients then rated their disfigurement using five items, a single item for patient appearance and ten items for dysfunction, all rated on a seven-point likert scale. Ratings of disfigurement by surgeons and nonsurgeons were found to significantly correlate with patients' ratings, indicating reliability between patients' self-reports and ratings from their healthcare team.

Reviewing QOL instruments used to assess the impact of disfigurement in HNC patients, the UWQOL was considered the instrument most well developed and validated to clinically evaluate appearance problems in HNC patients compared to the Head and Neck Survey, the EORTC QLQ-H&N35, the Derriford Appearance Scale 59 and the Derriford Appearance Scale 24 (Djan & Penington, 2013). Studies using the UWQOL and Derriford appearance scale have shown around 40% to indicate some concern about their appearance (Katre, Johnson, Humphris, Lowe, & Rogers, 2008; Millsopp et al., 2006). Additionally, 5% indicated they feel significant disfigurement and although this limits their activities, they still get out (Katre et al., 2008). The mean score for disfigurement on a patient-rated disfigurement scale with possible scores from 5 to 35, was 15.68, but scores ranged across the entire breadth of the scale (Katz et al., 2000).

In a study using the Derriford Appearance Scale 24, females reported higher appearance-related distress than females in the general population and male HNC survivors (Clarke et al.,

2013). At baseline, both fear of negative evaluation and dispositional optimism were significant predictors of appearance-related adjustment, with dispositional optimism remaining a significant predictor nine months later. Qualitative responses indicated that there is a link between appearance and disability, with patients describing how their difficulties with speaking and/or eating had a significant impact on how they appeared in public and how they were concerned about the visibility of their disfigurement in public. Coping strategies that patients found effective in managing their challenges about their appearance included hiding their disfigurement, focusing on positive aspects and reminding themselves they were lucky to be alive, and giving less importance to appearance (Clarke et al., 2013).

A study interviewing nurses and their patients a few days and 6 months after surgery found patients moved through the process of disfigurement from becoming disfigured within the hospital setting and not feeling different to others, to being a disfigured person in the community after discharge and experiencing others' silence, to becoming a person with a disfigurement, having alleviated the feeling of being left alone with disfigurement (Konradsen, Kirkevold, McCallin, Cayé-Thomasen, & Zoffmann, 2012). This process was described elsewhere as 'transitional cancer survivorship' as patients adjust from being acute survivors to being extended or permanent survivors (Miller, Merry, & Miller, 2008).

Identification of appearance-related concerns has been documented as being difficult in outpatient clinics due to them being busy, patients worrying it might take up too much of the doctor's time, or the doctors being reluctant to discuss issues they may not feel comfortable or confident with (Flexen, Ghazali, Lowe, & Rogers, 2012). In a sample where 75% of patients with early stage HNC did not need radical and invasive treatment, appearance was a concern raised by patients on the Patient Concerns Inventory in 9% of consultations and as a problem by patients on the UWQOL in 10% of consultations. Thirty-four per cent of patients with appearance concerns on the UWQOL also indicated anxiety as a problem, with 12% of those indicating appearance concerns on the PCI wanting to discuss appearance, but had no problem with anxiety.

Stigma and shame are also concepts that have been found to be pertinent through qualitative studies with HNC patients with disfigurement. Patients can feel stigma when others view their behaviour having caused the disease and/or when the disease results in visible disfigurement or

dysfunction (Crocker & Major, 1989; Sophie Lebel & Devins, 2008). A measure of Shame and Stigma for HNC was developed by Kissane and colleagues. Items loaded onto four factors of “sense of appearance”, “social and speech concerns”, “stigma” and “regret” (Kissane et al., 2012) and was shown to be reliable and valid. Using a battery of stigma measures, self-blame was not found to predict stigma, but disfigurement predicted stigma (Lebel et al., 2013).

In a review of the literature, nine studies examined body image as a psychological construct, with body image included as a study variable (Rhoten et al., 2013). In the first of a series of three studies, depression was found to predict body image issues (Fingeret, Vidrine, Reece, Gillenwater, & Gritz, 2010). The second study found 75% of patients reported body image concerns at some point since diagnosis and patients with speech and swallowing concerns had the highest number of body-related concerns and lower QOL than those with appearance-related concerns (Fingeret, Hutcheson, Jensen, Urbauer, & Lewin, 2012). The third study of the series found predictors for decreased QOL included greater body image dissatisfaction, greater number of body image concerns and time since surgery (Fingeret et al., 2011). In a quasi-experimental study, patients scheduled for surgery with flap reconstruction and receiving instructions in cosmetic rehabilitation, had improved satisfaction on the appearance evaluation, compared to patients receiving standard care (Huang & Liu, 2008). There was no overall change on body areas satisfaction, but higher satisfaction with patient’s body weight and face showed improvements at 12 weeks compared to baseline.

Dysfunction

Dysfunction refers to alterations in function, such as general functional deficits (e.g. fatigue), HNC specific functional deficits (e.g. loss of speech, swallowing) and loss of function in other areas such as the neck and shoulders (Rhoten et al., 2013). In a longitudinal study, HNC patients treated with surgery and/or radiotherapy showed limited deterioration of physical and role functioning and of many HNC symptoms at 6 months, as measured by the EORTC Head and Neck Cancer Module (de Graeff et al., 2000). Improvement was demonstrated after 6 months and after 36 months, with only physical functioning and symptoms of tastes/smell, dry mouth and sticky saliva rated as worse than at baseline. Being female, having a more advanced cancer stage and receiving multimodality treatment were factors associated with more symptoms and worse functioning. Physical symptoms included speech problems, appetite loss,

fatigue, cough, dry mouth and throat and swallowing problems, as well as pain (Chaukar et al., 2009; De Boer et al., 1999). Measuring head and neck dysfunction on a ten-item scale found the mean score to be 23.38, out of a possible 10 to 70 (Katz et al., 2000).

Eating is a significant loss of function in HNC patients and those diagnosed with oropharyngeal tumours have been shown to have worse scores on the eating scale than tumours from other primary sites (Terrell et al., 1999). Patients often report difficulties in function around eating, communication and pain.

As previously discussed in section 2.1.3, communication is a key challenge for patients following treatment. Research has demonstrated that concerns HNC patients have at the time of diagnosis differ from those long into survivorship (Meyer et al., 2004). Persistent concerns include those of speech intelligibility, with objective tests of communication found to correlate well with subjective self-perceptions of speech intelligibility (Meyer et al., 2004).

Summary

Disfigurement and dysfunction are two consequences of HNC which have the capability to cause psychological distress in patients by affecting body image (Figure 2.1). Women appear to have more appearance-related concerns than men and those receiving multimodality treatment have been shown to exhibit more symptoms and worse functioning than those receiving single modality treatment. The dysfunction related to HNC affects the fundamental human behaviours of eating and speaking which has a significant impact on how HNC patients appear in public.

2.1.5 Summary of the psychosocial impact of HNC

Reviews of the literature over the last 20 years have consistently provided evidence for the physical and psychological impact of HNC (De Boer et al., 1999; Dunne et al., 2016; Humphris & Ozakinci, 2006; Lang et al., 2013; Llewellyn et al., 2005; Moore et al., 2014; Rogers et al., 2007). As these studies have shown, there are a number of factors which can predict psychological distress in HNC patients and psychological factors, social factors, QOL, disfigurement and dysfunction are all closely associated and affect one another. The constructs found through the research presented in this chapter to either contribute to or be a consequence of psychosocial distress in HNC patients are synthesised in Figure 2.2. The next

section focuses on interventions that have been developed to help improve psychological outcomes in HNC patients.



Figure 2.2: Factors contributing to psychosocial distress in head and neck cancer

2.2 Interventions

Most of the psychosocial intervention studies carried out for HNC patients have included QOL, anxiety and/or depression as primary outcome measures. Some examples of interventions found through a search of the literature are summarised in Table 2.2 (D’Souza, Blouin, Zeitouni, Muller, & Allison, 2013; de Leeuw et al., 2013; Hammerlid et al., 1999; Handschel, Naujoks, Hofer, & Kruskemper, 2013; Jesse et al., 2015; Kangas, Milross, Taylor, & Bryant, 2012; Semple, Dunwoody, Kernohan, & McCaughan, 2009; van der Meulen et al., 2013; Vilela et al., 2006). The interventions involved regular sessions for a designated period of time providing a supportive environment for patients and delivering interventions to improve psychosocial outcomes through psychoeducational programmes, supportive counselling and Cognitive

Behavioural Therapy. Some of the interventions were group-based and others were individual sessions. All these interventions were found to be effective at achieving improvements in psychological outcomes and in some of these interventions the results were maintained longitudinally (Kangas et al., 2012; Semple et al., 2009; van der Meulen et al., 2013). The designs of these intervention studies however, were a mixture of quasi-experimental, feasibility, cross-sectional and only two were randomised controlled trials (RCTs).

An earlier review by Semple and colleagues suggested that there was evidence that psychosocial interventions generally provide an overall positive effect, but recognised that many of the studies had weaknesses in their methodology (Semple, Sullivan, Dunwoody, & Kernohan, 2004). Some education alone intervention studies failed to achieve favourable results. A recent Cochrane review conducted to assess the effectiveness of psychological interventions for improving QOL and psychosocial well-being for HNC patients found seven trials, either RCTs or quasi-RCTs, with no evidence to suggest that psychosocial intervention promotes QOL, anxiety or depression following the interventions (Semple et al., 2013). None of the studies included in Table 2.2 were included in the Cochrane review, as one of the criterion of the Cochrane review was that the intervention had to be tested in an RCT or quasi-RCT. The intervention studies implementing an RCT design and presented in the table, were published after the search in the review had been conducted in December 2012.

Although the interventions presented in Table 2.2 show promising results in their ability to achieve psychological improvements in HNC patients, only two of the intervention studies presented were tested in an RCT. As the review found interventions tested in either RCTs or quasi-RCTs to not be effective at achieving improvements in psychological outcomes, it may be that the other interventions presented here are flawed in their methodology. The review also showed that there is a paucity of research evaluating psychological interventions for this patient group. Therefore, there is a need for interventions to be tested within RCTs and to enable comparisons to be made more easily across interventions, standardised outcome measures need to be used. There may be a need to establish through RCTs, which factors are successful at achieving psychological improvements in order to develop an effective intervention.

Table 2.2: Interventions to improve psychological outcomes

Reference	Study design	Sample	Intervention	Outcome measures	Findings
Hammerlid et al.,1999 Sweden	Feasibility and effectiveness	13 newly diagnosed HNC patients living within 40km of the hospital; 34 control group those living further away 14 HNC patients one year post-treatment for psychoeducational program	Psychological group therapy (compared to control group) 1.5hours a week for 2 months, every second week for 2 months and once a month for 6 months Psychoeducational program	EORTC QLQ-C30 EORTC QLQ-H&N37 HADS Diagnosis, 3 and 12 months post-treatment	<ul style="list-style-type: none"> • Patients receiving psychological group therapy showed greater improvements than control group • Greatest benefit in psychological group therapy group concerned emotional functioning • At 1 year follow-up the therapy group had improved considerably and fewer patients than in the control group were considered probably or possible cases of psychiatric morbidity • Most of the functioning variables and symptoms improved after 1-week psychoeducational programme

EORTC QLQ-C30=European Organisation for Research and Treatment of Cancer core quality of life questionnaire; EORTC QLQ-H&N37=European Organisation for Research and Treatment of Cancer quality of life questionnaire head and neck cancer module; HADS=Hospital Anxiety and Depression Scale

Table 2.2: Interventions to improve psychological outcomes (contd.)

Reference	Study design	Sample	Intervention	Outcome measures	Findings
Vilela et al., 2006 Canada	Feasibility study – prospective, nonrandomised design	138 HNC patients; controls were matched to patients in the intervention group by stage of cancer and time since diagnosis	Short-term psychoeducational coping strategies intervention (Nucare)	QOL Depression Baseline, 3-4 months later	<ul style="list-style-type: none"> Intervention group showed improved physical and social functioning, global QOL, fatigue, sleep disturbance, depressive symptoms compared to the control group who showed no changes in QOL or depressive symptoms
75 Semple et al., 2009 Northern Ireland	Quasi-experimental design and compared to a control group	54 HNC patients completed treatment with evidence of psychosocial dysfunction; 25 intervention group, 29 control group	<p>Psychosocial intervention with treatment approach based on psychoeducation and Cognitive Behavioural Therapy principles</p> <p>Minimum of 2 sessions, maximum of 6 (average 4) lasting up to 90 minutes, biweekly</p> <p>Control group – ongoing review at the multidisciplinary HNC outpatient clinic and involvement as appropriate with members of the HNC team</p>	<p>HADS</p> <p>WASA scale</p> <p>HRQOL (UWQOLv4)</p> <p>1 week, 3 months post intervention</p>	<ul style="list-style-type: none"> The intervention group showed a significant reduction in psychological distress, improved social functioning and improved QOL scores which remained into the 3 month follow-up period

QOL=quality of life; HADS=Hospital Anxiety and Depression Scale; WASA=Work and Social Adjustment scale; HRQOL=health-related quality of life; UWQOL=University of Washington Quality of Life scale

Table 2.2: Interventions to improve psychological outcomes (contd.)

Reference	Study design	Sample	Intervention	Outcome measures	Findings
Handschel et al., 2013 Germany, Austria, Switzerland	Cross-sectional	1652 HNC patients at post-operative care appointments	Psychological interview	Depressive state Anxiety	<ul style="list-style-type: none"> 77.5% evaluated this as helpful 70.7% of patients did not want an interview Patients who wanted a psychological interview but who did not receive one showed significantly worse QOL than those patients who did not want an interview Interviews found to not meet the needs of the patient diminished QOL compared to not having an interview
D'Souza 2013 Canada	Non-randomised controlled trial	103 newly diagnosed HNC patients with stage III and IV primary or recurrent cancer; 50 intervention, 53 control	Tailored information (patient booklet, interactive computer booth, computer animation, DVD, database) compared to control intervention (no specific information resources, met with nurse for 15-45 minutes)	Distress thermometer HADS Baseline, 3 and 6 months	<ul style="list-style-type: none"> Lower levels of anxiety and depression were found in the intervention group than the control group Younger subjects were more depressed than older subjects

QOL=quality of life; HADS=Hospital Anxiety and Depression Scale

Table 2.2: Interventions to improve psychological outcomes (contd.)

Reference	Study design	Sample	Intervention	Outcome measures	Findings
de Leeuw et al., 2013 The Netherlands	Quasi-experimental, patients enrolled consecutively into two groups	80 HNC patients treated with curative intent 80 comparison group	Nurse-led follow up consultation during first year post treatment; 6x30 minute nurse follow up consultations Comparison group received conventional care; 5 year routine control schedule with 6x10 minute bimonthly visits to a head and neck surgeon in the first year post-treatment	Psychosocial adjustment measured using the Psychosocial Adjustment to Illness Scale-Self Report HRQOL measured using EORTC QLQ-C30 and QLQ-H&N35 1, 6 and 12 months after treatment	<ul style="list-style-type: none"> • Positive effects were found for the intervention group in HRQOL compared to conventional medical follow-up, but these were not significant • Greater improvements from baseline to 12 months in HRQOL scores were found in the intervention group compared to the comparison group at 12 months • Scores were lower in both groups at 12 months compared to baseline for psychological adjustment

HRQOL=health-related quality of life; EORTC QLQ-C30=European Organisation for Research and Treatment of Cancer core quality of life questionnaire; EORTC QLQ-H&N37=European Organisation for Research and Treatment of Cancer quality of life questionnaire head and neck cancer module

Table 2.2: Interventions to improve psychological outcomes (contd.)

Reference	Study design	Sample	Intervention	Outcome measures	Findings
van der Meulen et al., 2013 The Netherlands	RCT	205 HNC patients treated with curative intent; 103 intervention group, 102 control group	Nurse counselling and after intervention (NUCAI) compared to usual care; problem focused and patient driven, aims to help patients manage the physical, psychological and social consequences of their disease and treatment; maximum 6 counselling sessions of 45-60 minutes every 2 months over 1 year Care as usual – bimonthly by HNC specialists aimed at the treatment of complications and the detection of recurrences or second primary tumours	HADS HRQOL (EORTC QLQ-C30 and EORTC QLQ-H&N35) Depressive symptoms (CES-D) Baseline, 3, 6, 9, 12, 18, 24 months post treatment completion	<ul style="list-style-type: none"> Intervention group at 12 months showed significant improvement in emotional and physical functioning, pain, swallowing, social contact, mouth opening and depressive symptoms Intervention group remained significantly better than the control group at 18 months in global QOL, role and emotional functioning, pain, swallowing, mouth opening and depressive symptoms and at 24 months for emotional functioning and fatigue

HADS=Hospital Anxiety and Depression Scale; HRQOL=health-related quality of life; EORTC QLQ-C30=European Organisation for Research and Treatment of Cancer core quality of life questionnaire; EORTC QLQ-H&N37=European Organisation for Research and Treatment of Cancer quality of life questionnaire head and neck cancer module; CES-D=Center for Epidemiologic Studies Depression Scale; QOL=quality of life

Table 2.2: Interventions to improve psychological outcomes (contd.)

Reference	Study design	Sample	Intervention	Outcome measures	Findings
Kangas et al., 2013 Australia	Pilot RCT	35 primary, first-onset HNC patients aged 18-70 recommended to receive primary or adjuvant radiotherapy; 21 CBT, 14 supportive counselling	Brief early CBT intervention evaluated against a non-directive supportive counselling programme Both comprised 6x90 minute weekly sessions with structured homework activities and a 7 th booster session conducted 4 weeks following session 6	Acute cancer-related PTSD Anxiety (STAI) Depression (BDI) 1, 6 and 12 months post-intervention	<ul style="list-style-type: none"> Patients in both interventions reported declines in anxiety and depression over time and both were equal in their effects of reducing PTSD and enhancing perceived QOL Effects maintained at 6 and 12 months follow up
Jesse et al., 2015 USA	Cross-sectional evaluation	173 HNC patients psychiatrically evaluated by the integrated clinical health psychologist between May 2010 and August 2011	Evaluation of integrated psychological care and perceived benefit	Survey to determine whether perceived a benefit from having a psychologist integrated into HNC care <ul style="list-style-type: none"> Perceived availability/accessibility Effectiveness with distress management and QOL Impact of help with medical care Overall satisfaction 	<ul style="list-style-type: none"> Psychologist integrated into the evaluation and treatment of HNC patients was well received by staff, patients and patient supports Younger patients reported greater satisfaction than older patients Patients with reported psychiatric histories indicated more satisfaction in relation to managing distress than patients who denied psychiatric histories Current smokers tended to report lower satisfaction than past/never smokers

PTSD=post-traumatic stress disorder; STAI=State-Trait Anxiety Inventory; BDI=Beck Depression Inventory; QOL=quality of life

2.3 Implications for the patients' partner

As previously demonstrated, accompanying a diagnosis of HNC is a multitude of functional deficits as well as psychosocial implications for the patient. Understandably friends and family of the patient diagnosed are integral in the care of the patient due to the functional and psychosocial impact of this diagnosis and often become known as informal caregivers. Studies exploring the impact of a HNC diagnosis on informal caregivers, more often focusing on the partner of the patient, have found substantial impact on a number of factors including financial, information needs and psychological distress.

A recent review provided a thorough overview of psychological health of caregivers of HNC patients (Longacre, Ridge, Burtness, Galloway, & Fang, 2012), searching using different terms for head and neck cancer and for caregivers. Outcomes most frequently assessed in the studies included in the review were psychological distress, anxiety or depressive symptoms and caregiver perceived burden. A study measuring psychological distress with the HADS found 20% of HNC caregivers reported psychological distress (Verdonck-de Leeuw et al., 2007) and in a study using the Global Mental Health scale, 38% reported moderate to high distress (Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010). Two other studies also demonstrated anxiety symptoms suggestive of clinical anxiety in 30-40% of caregivers (Hodges & Humphris, 2009; Vickery et al., 2003) which is poorer than that found in the general population (Ostroff, Ross, Steinglass, & Ronis-tobin, 2004) and poorer than patients themselves (see section 2.1.1) (Hodges & Humphris, 2009; Vickery et al., 2003). Depressive symptoms were within the normal range (Hodges & Humphris, 2009; Vickery et al., 2003) and were equivalent to the general population. Caregivers also perceived moderate levels of caregiving burden (Chen et al., 2009) and expressed the need for psychological care for themselves to help them cope (Baghi et al., 2007). The review summarises the key factors reported to be associated with poorer psychological health in HNC caregivers as caregiver sociodemographic factors, time since the patient diagnosis, hours of care, lifestyle modifications, patient needs and treatment-related factors, and cancer recurrence (Longacre et al., 2012).

Further findings from the review presented mixed results for gender, age and educational level of the caregiver and their association with psychological health across studies. Confirmed in a couple of studies, caregiver psychological health appeared to be better with longer time since

diagnosis (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994; Ross et al., 2010) and poorer psychological health was associated with a greater number of hours caregiving (Ross et al., 2010). In qualitative studies, the themes emerging which reflected how caregiving for HNC patients leads to modifications in lifestyle were around the transition “from spouse to supportive caregiver”, self-neglect and managing psychological distress, changes in lifestyle and restricted living, and an “altered sense of time lived” (Röing, Hirsch, & Holmstrom, 2008; Watt-Watson & Graydon, 1995). Additionally, concerns about effects on patients’ socialising were noted (Watt-Watson & Graydon, 1995) and about their ability to continue providing care on an on-going basis (Mah & Johnston, 1993). Levels of caregiving burden were associated with the level of physical and daily living needs of the patient (Chen et al., 2009; Verdonck-de Leeuw et al., 2007) but spousal distress was not associated with patient’s self-rated functional impairment (Verdonck-de Leeuw et al., 2007). Finally, one study found caregivers had higher fear of recurrence than the patients themselves and that this was associated with psychological distress (Hodges & Humphris, 2009). This review provides a comprehensive overview of studies conducted into the psychosocial health of caregivers for the HNC patient and provides a substantial insight into the impact of caregiving for this patient group.

In studies published since the review, QOL in caregivers was found to decrease during the middle part of the patients’ treatment and caregiver burden increase over the course of the patients’ treatment (Badr et al., 2014; Nightingale, Lagorio, & Carnaby, 2014). Depression was also found to always be at lower levels in caregivers than patients. A systematic review of QOL in patient-caregiver dyads found no consensus in results (Sterba, Zapka, Cranos, Laursen, & Day, 2016).

An increase in patient-rated head and neck specific symptoms has an adverse effect on the psychosocial distress in patients and caregivers (Badr et al., 2014). Caregivers reported moderately high to high resilience, 27% had scores suggestive of the presence of anxiety and 10% had scores suggestive of the presence of depression (Simpson et al., 2015). Higher resilience was significantly associated with lower psychological distress and was independent of the severity of HNC.

Qualitative studies have given examples of psychological support needs of caregivers, with caregivers wanting information, honesty and empathy from clinical staff (Richardson, Morton, &

Broadbent, 2015a) and that practical support is the most useful support at 6 months post-diagnosis. Forty per cent of caregivers would have liked psychological support at diagnosis, and 33% still wanted psychological support at 6 months. Caregivers wanted to improve their understanding by having more information about HNC and its treatment, be able to express emotion, fears and concerns, and to discuss coping strategies. Caregivers also described their psychological distress, lack of knowledge and support in an interview study with relatives of HNC patients experiencing pain (Schaller, Liedberg, & Larsson, 2014). Relatives described their struggle with the patient's pain related to the treatment and in the context of their own situation. Relatives felt unable to relieve the patients' pain, felt in need of support from the health care service, had their own emotions to deal with and their altered daily activities and family roles due to the illness and treatment. Coping strategies in patients with terminal HNC and their caregivers have been described as being able to cope individually, using internal resources to cope, coping through support from others and coping together as a dyad (Foxwell & Scott, 2011).

HNC can also impact on caregivers financially and can result in caregivers becoming either under or unemployed (Balfe et al., 2016). Those with large debts or ongoing expenses could be vulnerable to cancer-related financial pressures and having access to medical and/or social welfare benefits may help mitigate financial distress.

Summary

A diagnosis of HNC has been shown to have a significant impact on the caregiver, as well as the patient. Caregivers have shown levels of anxiety that are worse than the general population and the patients themselves, demonstrating the substantial significance becoming a caregiver for a HNC patient has. Caregivers not only need to deal with their own emotions, but also support the patient through their psychological and physical needs, and greater caregiving hours are associated with lower psychological health. Studies have shown that caregivers would like to receive psychological support and these results suggest that this is something which should be offered to caregivers, as well as patients.

2.4 Summary

This chapter has presented a multitude of factors associated with psychosocial distress and QOL of HNC patients. A diagnosis of HNC is accompanied by long-term implications of treatment, often resulting in disfigurement and dysfunction. Interventions developed to help improve psychosocial distress have shown some promising results, but these need to be tested further and within RCTs. Friends and family of HNC patients are also significantly affected by the diagnosis and have their own emotional and practical needs and requirements for psychosocial support. The next chapter will focus on the psychosocial impact of the additional dimension of HPV as a causal factor, presenting findings in the cervical cancer screening context.

CHAPTER 3. PSYCHOSOCIAL ISSUES RELATING TO HPV IN CANCER

The research previously reported in chapter 2 has demonstrated the significant psychosocial burden of a diagnosis of head and neck cancer (HNC) not only on the patient, but also on the patient's caregiver. Human papillomavirus (HPV) is most well known for its association with cervical cancer and there has been a substantial amount of research carried out examining the psychosocial impact of HPV in the context of cervical cancer screening. As described in chapter 1, the relationship between HPV and HNC has now been well established, but there is currently very little work carried out examining the psychosocial impact of HPV-related HNC. It is therefore important to present what we currently know about the impact of HPV in the cervical cancer screening context. This will provide some insight into the potential impact HNC patients may face when told this diagnosis, which will be in addition to the already significant burden of their HNC diagnosis.

3.1 Psychosocial issues of HPV in the context of cervical cancer

Research conducted in the cervical cancer context has been carried out as part of the population-based screening programme for cervical cancer. Within such research, women are told they have HPV and are at risk for cervical cancer, which differs from the context of my thesis as I examine the impact of HPV in patients diagnosed with cancer.

3.1.1 Impact on relationships

Early research in women with genital HPV showed a high percentage of sexual impairments after treatment, fear of cancer and a negative impact on the emotional relationship with a partner (Filiberti et al., 1993). Reasons for changes in their emotional relationship with partners were the disease itself, fear of infecting the partner, pain during intercourse and forced use of condoms. A reduction in sexual enjoyment and frequency of sex has also been reported (Clarke, Ebel, Catotti, & Stewart, 1996).

Some women indicated that they had ceased sexual activity since learning of their HPV status. Disclosures in this sample of women focused on different aspects of HPV depending on who

they were disclosing to, with the focus being on its potential to lead to cervical cancer if talking to their mother or friends, and on its sexually transmitted nature if talking to their sexual partner (Daley et al., 2010).

3.1.2 Psychological outcomes

Based on the cervical cancer literature, an HPV infection can be accompanied by feelings of guilt, shame and depression (Clarke et al., 1996). A number of studies have found a substantial psychosocial impact associated with women testing positive for HPV. English-based centres participating in the piloting of HPV testing found women with borderline or mildly dyskaryotic smear results who were told they were HPV-positive, had significantly higher levels of anxiety, distress and concern compared to women who were HPV-negative, were not tested for HPV or were given normal results (Maissi et al., 2004). The women told they were HPV-positive also perceived themselves as being at a greater risk of developing cervical cancer than all other groups. Perceiving a greater risk of developing cervical cancer and not knowing the meaning of a smear result predicted anxiety, distress and concern, with younger age also being a predictor for anxiety. At six months after their results, the raised anxiety in the HPV-positive group and the differences between the groups for anxiety, distress and concern had disappeared (Maissi et al., 2005). Perceived risk of developing cervical cancer was higher in the HPV-positive and untested group at 6 months, compared to the HPV-negative or normal group. Concern about the smear test result was still elevated in women testing HPV-negative and was highest in those untested for HPV. Similar results were found in a cross-sectional survey in over 400 women where increased anxiety, distress and concern about sexual relationships were associated with testing positive for HPV and distress was markedly higher in women diagnosed with an abnormal smear accompanied by HPV (McCaffery et al., 2004). Anxiety and depression were both found to be elevated in a sample of Canadian women given an abnormal result compared to those given a normal result and this was clinically meaningful at 12 weeks (Drolet et al., 2012).

3.1.3 Knowledge of HPV and reactions to HPV diagnosis

Qualitative studies carried out with women tested for HPV alongside either a smear or colposcopy found women knew very little about cervical cancer or HPV (Waller, McCaffery, Nazroo, & Wardle, 2005). Some women were aware that HPV was linked to sexual activity, but

not that cervical cancer was linked to sexual activity, and therefore were shocked to discover its association with a sexually transmitted infection. Reassurance was provided by knowledge that HPV is common, it has no symptoms, it can lie dormant for many years, can clear up by itself and there is no need to raise concerns among sexual partners (McCaffery & Irwig, 2005; Waller et al., 2005).

Embarrassment, shame, fear and uncertainty have all been cited as initial reactions to a diagnosis of HPV (Taylor, Keller, & Egan, 1997). When specifically looking at data related to the diagnosis of HPV, being told of the HPV-positive nature of their test result was associated with adverse psychosocial consequences, primarily due to the sexually transmitted nature of HPV and its link to cervical cancer (McCaffery, Waller, Nazroo, & Wardle, 2006). Women felt stigma, anxiety, concern about their relationships and worry about disclosure of their test results to others. The terms 'unclean' and 'dirty' were used to describe some of the stigma they felt. Some women who were aware of the sexually transmitted nature of HPV, but who did not describe feelings of stigma, just saw it as an inevitable part of sexual activity. Those who were unaware of the sexually transmitted nature of HPV did not describe feelings of stigma. Questions were raised about where they had got the infection from and this sometimes led to women questioning if their partner had been unfaithful. Reports of receiving inconsistent information from health professionals contributed to their confusion and distress about the infection. Disclosing their HPV-positive result to their partner or family and friends was accompanied by anxiety and in some cases, in order to manage this anxiety, women chose not to disclose HPV (McCaffery et al., 2006). Similar results were found in the USA, with some women not intending to disclose their HPV-positive test result as they viewed this as stigmatising or shameful and were concerned it would be seen as a sign of having been unfaithful (Kahn et al., 2005).

More recent research has supported these findings with higher scores of worry and concern found in women given an abnormal smear result with a HPV-positive result compared to an abnormal smear only (Kwan et al., 2011; Wang et al., 2010). In addition, an analysis of interviews conducted with women who had received an HPV-related diagnosis, found five themes of stigma, fear, self-blame, powerlessness and anger emerging from qualitative data (Daley et al., 2010).

3.1.4 Information needs

In a research study conducted in Australia, women diagnosed with HPV after their smear test showed obvious confusion about HPV and what the HPV infection is, struggling to make sense of this information (McCaffery & Irwig, 2005). Many were confused about the association between high-risk HPV and genital warts which contributed to embarrassment and stigma they felt about HPV. Information needs of women were around transmission, prevention against catching and spreading the infection, importance of disclosing the HPV test result to future partners, how long the virus could lie dormant for and if it would completely clear, and how smoking could affect their cervical cancer risk. Almost all women said they had insufficient information about HPV and a high proportion looked for information elsewhere, most commonly on the internet. Women not understanding the information about their test result perceived themselves at higher risk of cervical cancer (McCaffery & Irwig, 2005). These findings were also found in Taiwan where women felt fearful of having cervical cancer and potentially infecting their partners, worry for themselves and their partner, and suspicion about the results or their partner's faithfulness (Lin, Jeng, & Wang, 2011).

A number of studies have found that a lack of information and uncertainty has contributed to feelings of anxiety, stigma and shame (Daley et al., 2008; Waller, Marlow, & Wardle, 2007), confusion and distress (Kosenko, Hurley, & Harvey, 2012; McCaffery et al., 2006; McCaffery & Irwig, 2005), and has resulted in perceiving a higher risk of cervical cancer (Drolet et al., 2012). Uncertainty documented by women was found to be around the meaning of their diagnosis, the potential progression of the infection, finances, not knowing the source of infection, disclosure to current and prospective sexual partners, insufficient information about the implications for sex and reproduction, and about whether the HPV vaccine would prevent against future infections with HPV (Kosenko et al., 2012).

As a lack of information contributes to the negative psychosocial impact experienced by many women, it is important for health professionals to recognise this and address psychosocial and educational needs throughout the treatment and follow-up process, provide support to facilitate coping, and provide education to promote optimal self-care (Linnehan & Groce, 2000).

Providing written information for patients to take home and refer back to and share with their family and friends has been seen as important to help ease uncertainty (Linnehan & Groce,

2000; Rubin & Tripsas, 2010). As the internet has also been cited as a popular source of health information, it is also important for evidence-based, accurate information to be made available online.

3.2 Possible implications for patients diagnosed with HPV-related head and neck cancer

For a patient diagnosed with HPV-OSCC they have been given a diagnosis of cancer and of a sexually transmitted infection, and told that their cancer has been caused by this sexually transmitted infection. As presented in section 3.1.2, women told of their diagnosis of HPV in the cervical cancer screening context indicated substantial psychosocial burden. Common patient concerns related to HPV in HNC have been documented to be how, when and why they got their cancer (Fakhry & D'Souza, 2013). The answers to these questions have implications both for the patient and their past, present or future partners. The answers to these questions are often complex and, due to a lack of available evidence, sometimes unanswerable (Chu, Genden, Posner, & Sikora, 2013).

A small number of quantitative studies have begun to measure quality of life (QOL) and the informational and psychosocial needs of HPV-OSCC patients (Maxwell et al., 2013; Milbury, Rosenthal, El-Naggar, & Badr, 2013) which are discussed in chapter 4. A small qualitative study with HPV-OSCC survivors found that some felt stigma or embarrassment related to their diagnosis and that nearly half were worried about infecting their partner (Baxi et al., 2012). As discussed in section 1.2.4, some studies have found indications of transmission of oral high-risk HPV between partners (Agrawal et al., 2008; Haddad et al., 2008). One study found persistent oral HPV infection in one spouse to be a significant risk factor for oral HPV infection in the other partner (Rintala, Grénman, Puranen, & Syrjänen, 2006).

As discussed earlier in section 2.1.1, younger age has been found to be a factor which contributes to psychosocial distress in HNC patients. As HPV-OSCC patients are more likely to be younger, it is possible that they may experience greater psychosocial distress than older patients with HPV-negative HNC. This also means that more parents of young children are being diagnosed with HPV-OSCC. A qualitative study found HNC patients with young children experienced fear of missing milestones in their children's lives and fear of telling their children

about their diagnosis (Semple & McCance, 2010). The dysfunctional effects of treatment also had an impact on family activities and following treatment they had a desire to get back to day-to-day life. Patients with HPV-OSCC who are younger are keen to return to their normal lives, which could also have implications for rehabilitation needs.

3.3 Summary

As chapters two and three have demonstrated, a diagnosis of HNC and a diagnosis of an HPV infection independently have a substantial negative psychosocial impact. Chapter two demonstrates the significant impact that a diagnosis of HNC has on the patient in terms of disfigurement and dysfunction associated with its treatment, affecting levels of psychological distress and quality of life, as well as how the patient perceives reactions from others and how their life has changed in a social context. A diagnosis of HPV-OSCC also has implications of caregiving responsibilities and a possible reduction in sexual intimacy between patients and their partners. The partner will also have their own informational needs alongside their fears and concerns.

Chapter three provides evidence that in the cervical cancer screening context, a result which shows infection with HPV can result in psychosocial distress. Women receiving this result in the context of screening have expressed feelings of embarrassment, worry, and stigma and have been concerned about transmitting the infection to their partner or future partners. Although these findings are in the context of cervical cancer screening and in women being told of abnormal results, but not of a cancer diagnosis, these findings provide a substantial body of evidence and a starting point to exploring the psychological impact of HPV in other cancers.

The evidence from both the cervical cancer screening and HNC literature suggests that the combination of these could lead to psychosocial distress in HPV-OSCC patients being amplified. A great number of factors contribute to psychosocial distress in HNC patients and there is an opportunity for health psychologists and behavioural medicine specialists to use their expertise to develop ways in which the impact of these factors could be alleviated.

3.4 Psychological theories

Social cognition models are primarily focused on components which interact in a linear nature to predict health behaviours, such as attending for cervical cancer screening or being vaccinated against HPV. This includes models such as the Health Belief Model (Rosenstock, 1974) and The Theory of Planned Behaviour (Ajzen, 1991). Applying theory can help guide and focus research and can be useful in explaining health outcomes. Theory also allows knowledge to accumulate so that better models to understand behaviour can be developed. How patients cope and appraise illnesses cannot be explained by these models and therefore models are needed which take into account the dynamic processes involved. Understanding patients' beliefs about their illness and how this impacts appraisal of their illness is important to ensure interventions to change behaviour can be targeted appropriately.

3.4.1 Psychological models of illness perceptions/adjustment

The use of psychological theory is scarce in research previously conducted examining the psychosocial impact of HNC. The dynamic process through which patients' beliefs and appraisals of their illness influence their emotional outcomes is often termed 'adjustment'. Adjustment has commonly been defined as 'the presence or absence of diagnosed psychological disorder, psychological symptoms or negative mood' (Stanton, Revenson, & Tennen, 2007, p568). Although my thesis is pragmatic and not theory-driven, I recognise that there are some useful theories of psychological adjustment which could be applied to examine the issues raised in this thesis and, where appropriate, these are drawn upon in the discussion sections of the empirical chapters. These theories of psychological adjustment are dynamic, examining patients' beliefs and responses about an illness following the acquisition of new health information in changing contexts. Firstly, it is important to look at examples of theories which help explain how patients may understand their illness and how this may affect ways in which they cope with their illness.

3.4.1.1 Common-Sense Model of Self-Regulation

Leventhal's Common-Sense Model of Self-Regulation (CSM) theorises that lay cognitive illness representations fall into five dimensions: identity, cause, consequences, timeline, curability or

controllability (Leventhal et al., 1980). In the context of this research, this refers to how patients understand their HNC diagnosis through these five dimensions.

Identity is the label given to the health threat (e.g. cancer), as well as experiences of the threat such as any symptoms or functional changes; cause relates to patients' perceptions of what might have determined their cancer (e.g. HPV); the consequences of the illness refer to the physical, psychological, social and economic impact that the illness may have on the patient's life (e.g. loss of speech); timeline refers to the duration of the illness, including the development and the recovery (e.g. how long they may have cancer) and whether this is acute, chronic, or cyclical; curability or controllability refers to the extent to which the patient believes their illness can be prevented or treated (e.g. prognosis). The CSM assumes that these five dimensions explain how people attempt to cope with illness.

The Illness Perception Questionnaire (IPQ) was developed as a quantitative measure of these dimensions (Weinman, Petrie, Moss-Morris, & Horne, 1996). More recently, the curability or controllability dimension of the CSM was extended to include personal and treatment control, illness coherence and emotional representations and the Revised Illness Perception Questionnaire (IPQ-R) was developed to include these dimensions (Moss-Morris et al., 2002). Personal control refers to how much a person feels in control of their own illness; treatment control is the perception of how effective the treatment will be on their illness; and illness coherence refers to how much understanding a person has about their illness. Emotional illness representations are recognised as an additional parallel process to cognitive illness representations and both are included in the CSM (Figure 3.1) (Leventhal et al., 1997). Emotional representations may include anger, anxiety or fear, and responses to these representations may include seeking social support or denying the existence of the illness. The model posits that both cognitive and emotional representations of illness influence coping strategies, the success of which are later appraised and may lead to the representation being adapted and a new coping strategy being implemented. Although the cognitive and emotional pathways are parallel processes, they also influence each other.

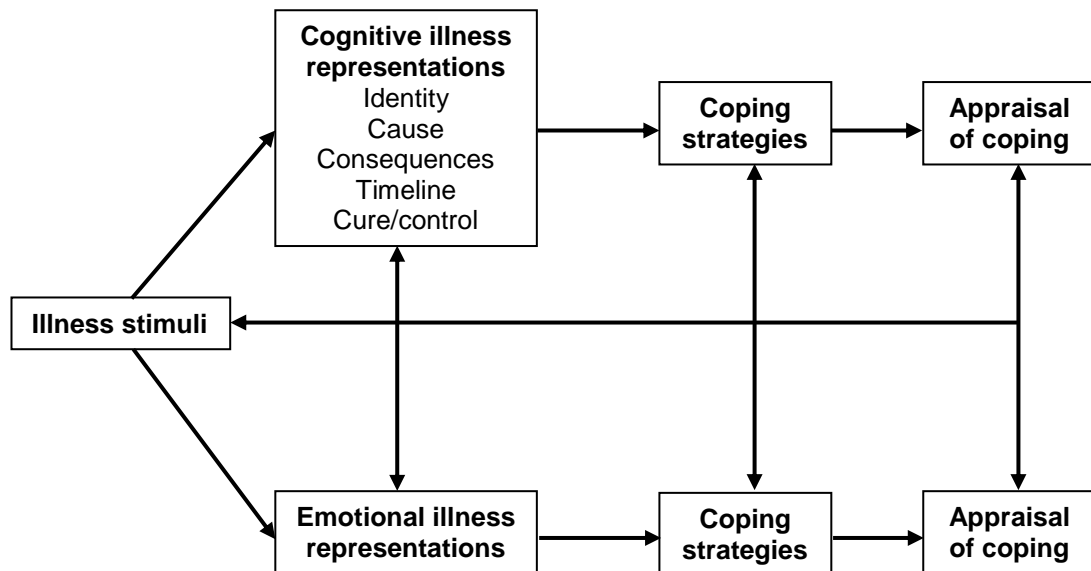


Figure 3.1: Common-Sense Model of Self-Regulation adapted from Leventhal et al., 1997

These illness representations have mainly been applied to chronic illnesses and a recent systematic review found over 50 studies assessing illness representations in cancer patients using the IPQ, the IPQ-R and the Brief Illness Perception Questionnaire (B-IPQ; Broadbent, Petrie, Main, & Weinman, 2006) (Richardson, Schüz, Sanderson, Scott, & Schüz, 2016). This systematic review and meta-analysis found evidence of associations between illness representations, coping behaviours and cancer illness outcomes (Richardson et al., 2016). Specifically, those patients with a greater identity, timeline, consequences, emotional representations and lower personal control, treatment control and illness coherence adopted maladaptive coping strategies and experienced more negative illness outcomes such as higher anxiety. The reverse reflected adaptive coping behaviours and more positive illness outcomes, such as higher QOL.

This theoretical framework has been applied in a few studies with HNC patients, using the IPQ-R to predict fear of recurrence (Llewellyn, Weinman, McGurk, & Humphris, 2008) and QOL (Dempster et al., 2011; Llewellyn et al., 2007; Scharloo et al., 2005, 2010). The findings from these studies show various relationships exist between pretreatment illness perceptions with coping over time. For example, better QOL was associated with less belief of the disease being cyclical, lower internal disease attributions and lower emotional response to disease (Scharloo et al., 2005), and changes in depression and anxiety over time were associated with a change in illness perceptions, with illness perceptions and coping variables contributing to the majority

of explained variance in psychological distress (Dempster et al., 2011). Patients perceiving less severe consequences, more personal control, being more likely to understand their condition and being less likely to believe their HNC was caused by stress or poor emotional health were less likely to report poor psychological health (Dempster et al., 2011). This theoretical framework has limited evidence of use in HNC, but results thus far are suggestive that HNC patients' illness representations may be useful in explaining psychological outcomes.

3.4.2 Transactional Model of Stress and Coping

As the CSM model suggests, patients' illness representations influence how they cope with their illness. In the context of this thesis, coping influences how patients and their family members experience the diagnosis and the level of potential psychological impact. Problem-focused coping and emotion-focused coping have been suggested as strategies for coping with stress (Lazarus & Folkman, 1984). Problem-focused coping is aimed at the stressor (e.g. cancer) and emotion-focused coping is aimed at reducing distress (e.g. anxiety). Stress exists when a person is confronted with a stressor; for example a diagnosis of cancer that they are unable to manage. Coping refers to their efforts to deal with the stressor which can result in the removal of the stressor or a reduction of its adverse impact on the person. Lazarus and Folkman (1984) developed a framework to include dynamic processes involved in the appraisal of stress, which is known as the Transactional Model of Stress and Coping (Figure 3.2). This model views stress as a transaction between the person and the environment and involves both primary and secondary appraisals of the stressor (Wenzel, Glanz, & Lerman, 2002). The impact of the stressor is mediated by these appraisals, as well as the psychological, social and cultural context.

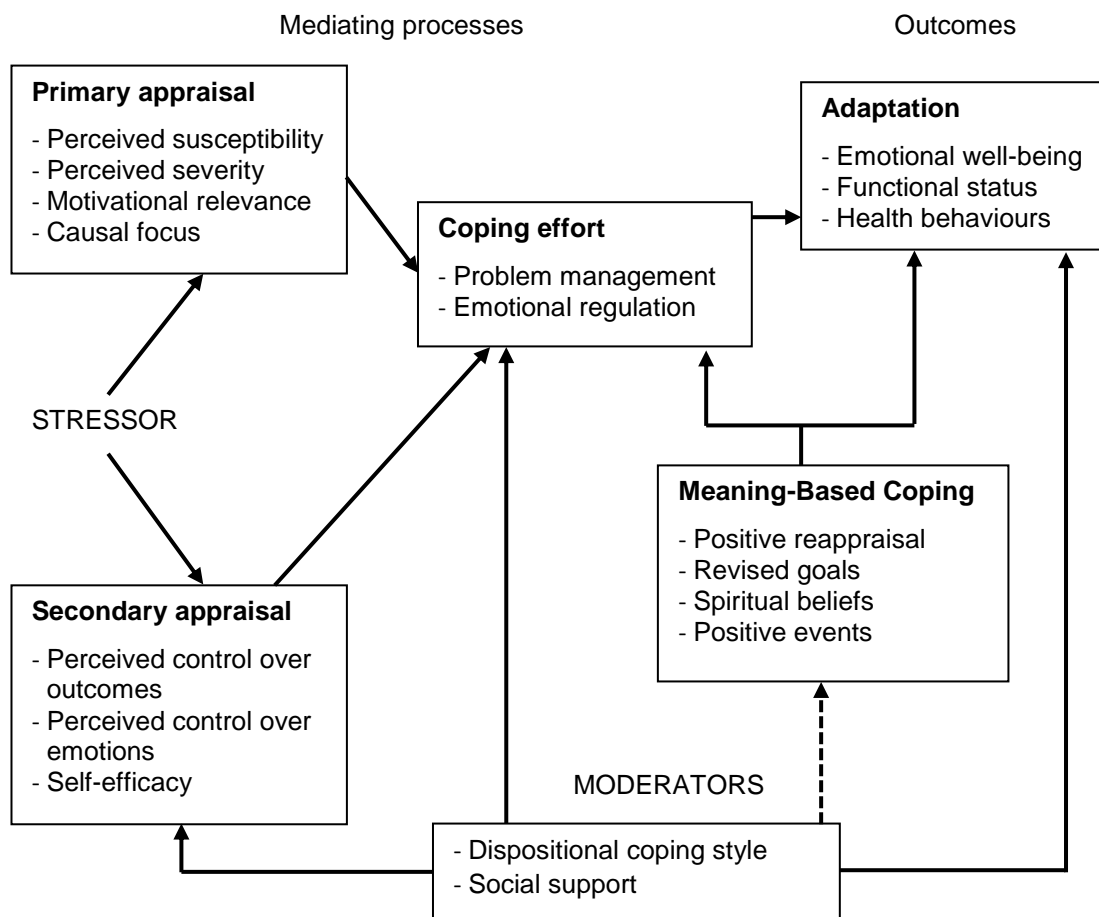


Figure 3.2: Transactional Model of Stress and Coping (Glanz and Schwartz., 2008)

Primary appraisal is the judgement made as to whether an event, such as a cancer diagnosis, is controllable or stressful. Perceived susceptibility and perceived severity are two examples of primary appraisals. The model suggests that patients perceiving themselves to be at risk and perceiving the stressor to be severe will either encourage patients to cope with the stressor, or may lead patients becoming distressed. Motivational relevance refers to the impact the stressor may have on a person's life and causal focus to how responsible a person might feel for the stressor. High motivational influence (e.g. perceiving a high impact on their life) and high causal focus (e.g. self-blame) may lead to anxiety, guilt and depression. Secondary appraisal refers to a person's perception of whether they have the resources or ability to manage the stressor. Perceived control over outcomes and emotions, and a person's self-efficacy, all contribute to a person's appraisal of their ability to deal with the stressor.

The association between these two appraisal systems and the outcome are mediated by problem and/or emotion-focused coping strategies, as discussed earlier. Problem-focused

strategies are predicted to be most useful for stressors that are perceived as controllable and emotion-focused for stressors that cannot be changed. Meaning-based coping strategies are also used to cope with health stressors and can induce positive emotion (Folkman, 1997). Active coping strategies have often been shown to have psychological benefits in comparison to avoidant or disengaging strategies (Carver et al., 1993; Fawzy et al., 1990). The outcomes refer to how the person has adapted to a stressor after their primary and secondary appraisals, mediated by coping strategies.

This model has been applied in a small interview study of eight HNC patients as a framework to describe the appraisal and coping processes of these patients following their diagnosis (Moore et al., 2014). Environmental factors were found to be influential to patients' appraisal and coping processes and structured support from health professionals positively impacted patients' ability to cope during their treatment. Those patients who had less social support were found to have less effective coping strategies.

3.4.3 Models of behaviour change

The interaction between patients and health professionals in their discussions of HPV in the context of HNC, may be influential in shaping patients' beliefs and appraisals about their diagnosis. As beliefs about illness can be shaped by information provided, it was important to draw on an all-encompassing model of behaviour to understand the components influential in discussing HPV and how these may be targeted in interventions.

3.4.3.1 The Capability Opportunity Motivation-Behaviour Model

The Capability Opportunity Motivation-Behaviour (COM-B) model is the central hub of the Behaviour Change Wheel (BCW), which was developed to provide a framework encompassing all the common features of previous behaviour change frameworks, and which is linked to a model of behaviour that can be broadly applied to any behaviour (Michie, van Stralen, & West, 2011). The COM-B model is the starting point in the development of interventions, as it identifies the source of behaviour. The model posits that an individual's capability, opportunity and motivation to enact a behaviour interact with each other to generate behaviour. Capability refers to an individual's psychological and physical capacity to carry out the behaviour, which includes their knowledge and skills. Motivation involves reflective processes (e.g. attitudes and

beliefs), and automatic processes (e.g. wants and needs, desires). Opportunity reflects physical (e.g. time, resources, location) and social (e.g. social cues and cultural norms) factors.

Figure 3.3 illustrates how these components interact and influence each other. This model can be used for the development of interventions aimed at changing behaviour. In the context of this thesis, the behaviour to be changed is health professionals discussing HPV with their patients (see chapter 7).

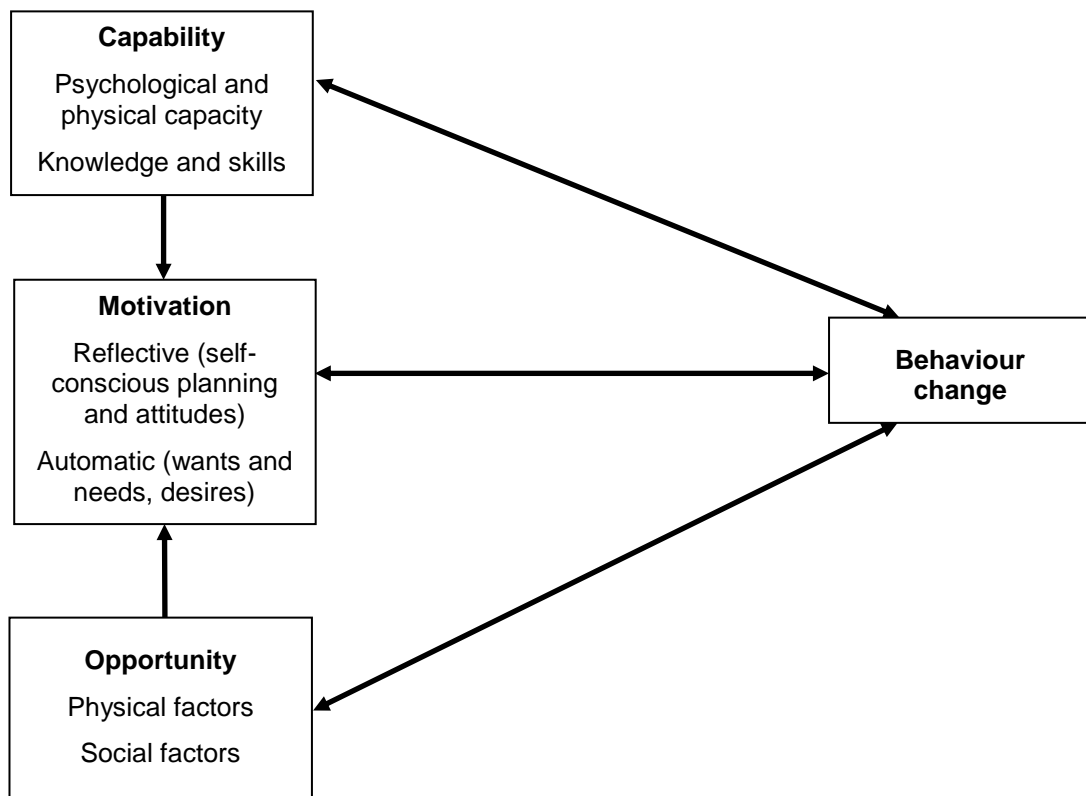


Figure 3.3: The COM-B Model (Michie et al., 2011)

3.4.3.2 The Information-Motivation-Behavioural Skills model

The Information-Motivation-Behavioural Skills (IMB) model (Fisher & Fisher, 1992), asserts that behaviour-specific information, motivation and behavioural skills are necessary for an individual to perform a health behaviour. Information that is directly relevant to performing the health behaviour is necessary for performing that health behaviour. Motivation includes both personal (e.g. attitudes) and social motivations (e.g. perceived social support) for engaging in a health behaviour. Finally, behavioural skills include both objective skills and self-efficacy for performing the health behaviour. Figure 3.4 illustrates how these three components interact, with the interaction of information and motivation inducing behaviour change through behavioural skills.

Information and motivation can also work directly to induce behaviour change, which may be when the behavioural skills required to induce a behaviour change are more complex (Misovich, Martinez, Fisher, Bryan, & Catapano, 2003). In the context of this thesis, the health behaviour requiring a change is health professionals discussing HPV and this is illustrated in Figure 3.4.

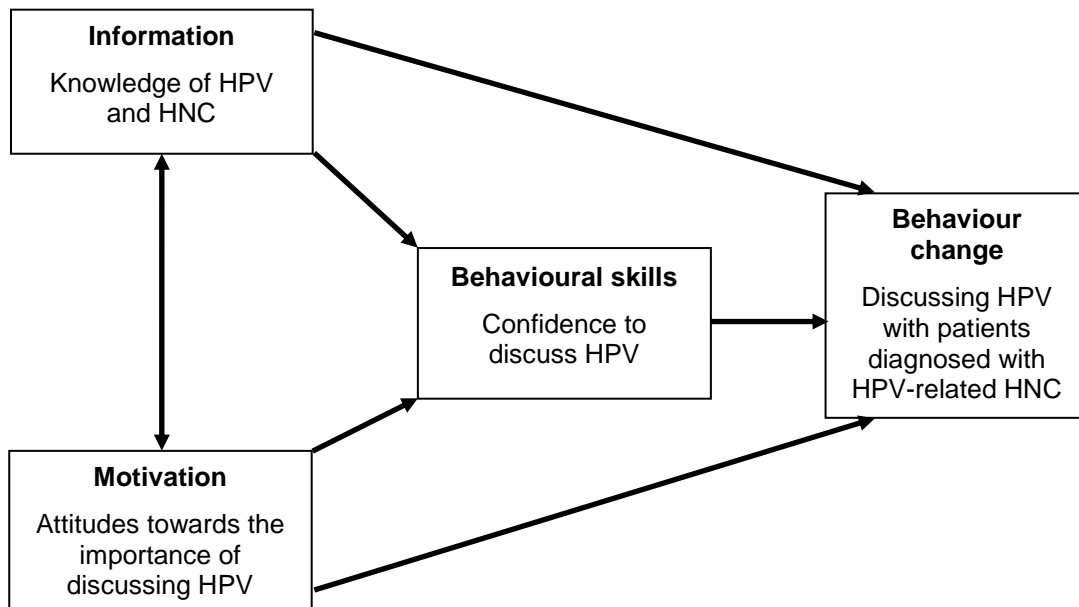


Figure 3.4: Information-Motivation-Behavioural Skills model (Fisher & Fisher, 1992)

3.4.4 Summary

The CSM and The Transactional Model of Stress and Coping provide a theoretical underpinning into our understanding of patients' responses to illness and how these are appraised. The dynamic processes involved in these two models may help us understand patients' representations after a diagnosis of HPV-OSCC, how these may influence their coping attempts, and how this may change over the period of their treatment and recovery. Theories of behaviour change such as the COM-B model are helpful for targeting areas in the development of interventions, such as those which may facilitate discussions of HPV between patients and health professionals.

3.5 Aims of thesis

As the evidence presented in the first three chapters of this thesis shows, there is potential for patients diagnosed with HPV-OSCC to experience significant psychological distress. However, with limited research specifically looking at this particular group, the extent to which

psychosocial distress is experienced by HPV-OSCC patients is unknown. In addition it is unclear what different populations know about HPV and HNC and what information they have been provided with by the media and health professionals; or the impact of an HPV-OSCC diagnosis on both patients and their partners. Using a series of studies implementing a range of methodology, this thesis will improve on our understanding of the psychosocial impact of HPV-OSCC across different populations.

More specifically, this thesis aims to:

1. Review the existing literature exploring the psychosocial impact of HPV-OSCC on patients and knowledge of HPV and head and neck cancer among the public, patients and health professionals
2. Examine the UK media for coverage of the link between HPV and head and neck cancer in order to establish the information presented to the public about HPV and head and neck cancer
3. Explore the views and experiences of UK health professionals caring for patients with HPV-positive head and neck cancer
4. Explore the views and experiences of patients diagnosed with HPV-positive head and neck cancer and their partners
5. Develop information materials to provide information for patients diagnosed with HPV-related head and neck cancer and partners of those diagnosed with HPV-related head and neck cancer

These aims are addressed in a series of six studies, addressing the following research questions:

Study 1: A systematic review of the literature

- 1) What is the psychological impact of an HPV diagnosis in the context of head and neck cancer according to the existing literature?

- 2) What is known about HPV-related head and neck cancer in different population groups according to the existing literature?

To provide context, rationale and background to my thesis, study 1 is a systematic review which examined the psychosocial literature in HPV-OSCC and the literature measuring the knowledge of the relationship between HPV and HNC. I was invited to write this systematic review for a special Head and Neck Oncology edition of Clinical Oncology. The database search was carried out in December 2014.

Study 2: UK media coverage of the link between HPV and HNC

- 3) How frequently has the relationship between HPV and HNC received coverage in the UK media?
- 4) What information is included in media articles covering the relationship between HPV and HNC?

At the time this study was conducted, my focus was on the interaction between health professionals and patients diagnosed with HPV-OSCC and the findings presented in study 3 demonstrated some important messages that should be communicated about HPV. Due to the timely disclosure from Michael Douglas about his throat cancer being caused by HPV prior to the start of my PhD, this offered an opportunity to assess the content of the media at a time when HPV-related HNC was receiving a lot of media attention. Although this study does not fit directly with the other aims of the thesis, it was considered important and too good an opportunity to miss to establish what messages about HPV-OSCC were communicated to the general population through the media. These research questions were addressed using a content analysis of articles published in the media providing coverage of the relationship between HPV and HNC. The search was conducted in August 2014.

Study 3: An exploratory interview study with health professionals

- 5) What are the experiences and attitudes of health professionals in the UK about discussing HPV with HPV-OSCC patients?

This study was needs driven and the starting point of my thesis, as my supervisor Dr Jo Waller was contacted by a health professional worried about the increasing number of HPV-OSCC

cases and was concerned about their ability to communicate to patients about HPV. This was therefore the first study conducted as part of my thesis and it adopted an exploratory qualitative study design to explore the experiences, attitudes and beliefs relating to HPV-OSCC in health professionals. This study was carried out in June 2013.

Study 4: A survey of health professionals

- 6) What are the experiences and attitudes of different groups of health professionals in the UK and Ireland who care for patients with HPV-OSCC?

Due to the exploratory qualitative nature and small number of health professionals in study 3, this study involved the development of a survey based on the results from study 3. A survey-based quantitative study was carried out, designed to explore the knowledge, experiences, attitudes and beliefs relating to HPV-OSCC in a larger sample of different health professional groups. This study was carried out between October and December 2015.

Study 5: A qualitative interview study with patients diagnosed with HPV-OSCC and their partners

- 7) What is the psychosocial impact on patients being diagnosed with HPV-OSCC?
- 8) What is the psychosocial impact on partners of patients who have been diagnosed with HPV-OSCC?

The systematic review in study 1 showed limited literature available examining the psychosocial impact of HPV-OSCC and studies 3 and 4 demonstrated some of the concerns patients express to health professionals about HPV. Therefore a qualitative study with patients and their partners was designed to explore their experience of being diagnosed or of their partner being diagnosed with HPV-OSCC and what this may mean to them. This study was carried out between September and November 2015.

Study 6: The development of patient information materials

As the previous studies had found health professionals and patients to have information needs about HPV-OSCC, this study drew together the findings from all the previous studies, to design an information booklet to answer frequently asked questions of health professionals, patients

and their family members. This was also developed as a discussion tool to facilitate the discussion of HPV between health professionals, patients and their family members. The information booklet began development in December 2015 and was completed in April 2016.

These studies are not presented in the order in which they were conducted, but are ordered in a way in which the narrative flows better. Figure 3.5 illustrates the dates each study was carried out.

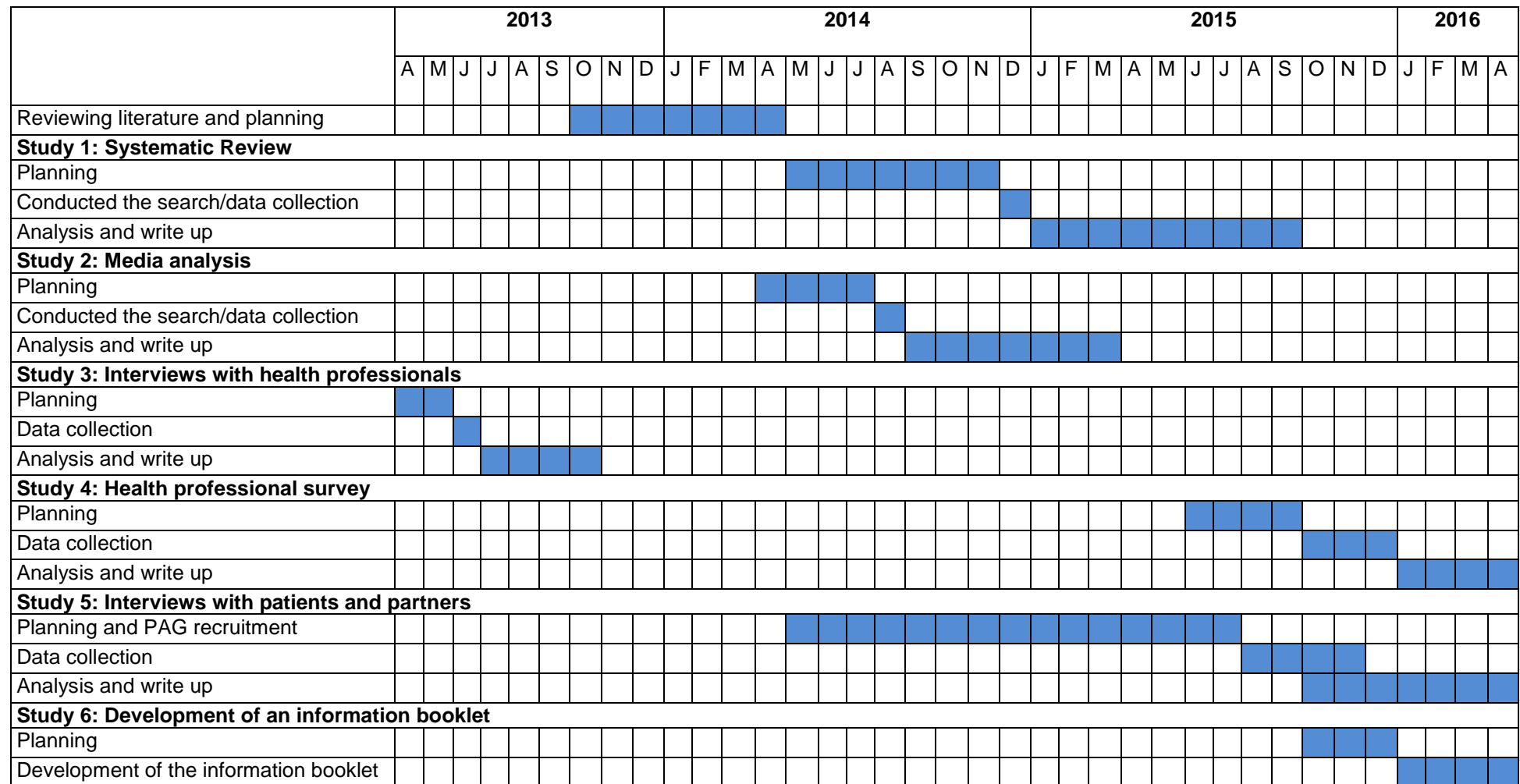


Figure 3.5: Timeline illustrating the dates each study was conducted

CHAPTER 4. A SYSTEMATIC REVIEW OF THE LITERATURE (STUDY 1)

4.1 Introduction²

As detailed in chapter 1, it is now clear that an increasing proportion of head and neck cancer (HNC) cases are caused by HPV (Gillison et al., 2012; Mehanna et al., 2013; Näsman et al., 2009; Rietbergen et al., 2013). Chapter 2 presented evidence of a diagnosis of HNC being associated with a well recognised psychosocial impact, but research exploring this in patients with HPV-related HNC has yet to be synthesised.

Also detailed in the previous chapters, we know from the cervical cancer literature that the sexually transmitted nature of HPV can lead to psychological challenges. As the link between HPV and HNC has been established, and HPV is sexually transmitted, there has been increasing recognition of the need for guidance on how to discuss HPV with patients (Chu et al., 2013; Fakhry & D'Souza, 2013; Finnigan & Sikora, 2014). Sections 2.1, 2.2 and 3.1 of this thesis show the contribution of behavioural and psychological science to understanding and addressing psychosocial issues associated with both HNC and HPV. It is also important to assess knowledge of the association between HPV and HNC among different populations, to identify gaps in knowledge and inform communication strategies.

Research has begun to explore what the public know about HPV and HNC and how an HPV diagnosis affects patients. Knowledge of HPV appears to have increased following the introduction of the HPV vaccination which is now offered to adolescents in most developed countries (Kelly, Leader, Mittermaier, Hornik, & Cappella, 2009; Patel, Jevé, Sherman, & Moss, 2016). In the context of cervical cancer, an online survey of adults in the UK, USA and Australia following the introduction of the HPV vaccination showed 61% reported having heard of HPV (Marlow, Zimet, McCaffery, Ostini, & Waller, 2013). By contrast, public awareness of the signs and risk factors for HNC has been shown to be poor (Warnakulasuriya et al., 1999). In the HNC

² The search for this study was conducted in December 2014. Literature available during this period which contributed to the rationale for this study is included in the introduction. Literature published after the analysis for this study was performed, is included in the discussion. A version of this chapter has been published in *Clinical Oncology* (Appendix 4.1).

clinical context, an overview paper has shown that few resources currently exist to answer patient's concerns about how, when and why they got their cancer (Fakhry & D'Souza, 2013), the answers to which can have implications both for the patient and their past, present or future partners.

My review draws together findings from the emerging literature and identifies priorities for a behavioural science research agenda in this field. The evidence from both the cervical cancer and HNC literature suggests that there may be greater psychological distress in these patients due to the combination of both a diagnosis of cancer and of HPV. The review aimed to answer the first two research questions of this thesis:

- 1) What is the psychological impact of an HPV diagnosis in the context of HNC?
- 2) What is known about HPV-related HNC in different population groups?

4.2 Methods

4.2.1 Search methods for identification of studies

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). I developed the search terms in consultation with a librarian at University College London and through extracting key terms from previous review papers and relevant primary research. The initial search terms covered 1) the two health conditions of interest (e.g. HPV, human papillomavirus, head and neck cancer) and 2) psychosocial outcomes of interest (e.g. psychosocial, depression, anxiety, quality of life). These psychosocial factors were chosen for the search based on previous reviews with HNC patients and a scoping exercise of the current literature. On examination of the papers found with the initial search strategy, it was evident that papers also being included were those which examined knowledge of the link between HPV and HNC. Therefore I added a third search term to the search strategy; 3) knowledge. It was deemed important to also assess knowledge of the relationship between HPV and HNC in different populations to identify groups where knowledge is limited and where communication campaigns could be targeted. Assessing knowledge in the population also helps to understand the amount of information people who are diagnosed with HPV and HNC may be receiving. The full search strategies and the number of papers found for each database are shown in Appendix 4.2. Initial search terms were later

refined based on common text words from relevant articles retrieved from the search. I accessed MEDLINE, Embase and PsycINFO databases through Ovid databases and searched from inception to present in December 2014. I adapted the search terms for CINAHL Plus and Web of Science. Boolean operators were used to combine terms such as 'head and neck cancer OR oral cancer' AND 'human papillomavirus OR HPV'. These databases were chosen based on previous review papers in this field and because all databases complement each other and allow a broader scope of coverage. There were no language or date restrictions applied to the search. I searched the reference lists of included studies for additional relevant papers and the grey literature using OPENSIGLE (opensigle.inist.fr). No papers were found from the grey literature. I downloaded the results of the literature search into Endnote and removed any duplicate articles.

4.2.2 Inclusion and exclusion criteria

Studies were included if they 1) reported original research (qualitative or quantitative), 2) mentioned HPV and HNC, 3) measured an aspect of the psychosocial impact of the diagnosis of HPV-related HNC as the dependent variable and/or 4) measured knowledge of the association between HPV and HNC. Studies were excluded if they were not written in English, did not report original research or were conference abstracts.

4.2.3 Selection procedure

Dr Jo Waller and I screened all the titles of the articles and excluded articles if they were not written in the English language or were clearly irrelevant to the review. Disagreements were resolved by discussion and reasons for inclusion/exclusion were noted. Dr Laura Marlow and I screened all the abstracts of the remaining articles, looking more specifically for articles mentioning HPV. Authors of conference abstracts that appeared to meet the eligibility criteria were contacted to request a copy of the full paper if it was available. Those not submitted or published in peer-review journals were excluded and one author did not reply so this paper was also excluded. Disagreements were resolved by discussion and reasons for inclusion/exclusion were noted. Articles that appeared to meet the inclusion criteria based on the title and abstract screen were obtained for full-text review (Figure 4.1). Copies of articles that could not be assessed for relevance based on the title and abstract screen were also obtained to determine eligibility based on full-text review.

I conducted the full-text eligibility review with Dr Laura Marlow and we both independently recorded reasons for exclusion of papers. Reasons for excluding studies included the article not containing i) any original data relevant to our eligibility criteria, ii) not mentioning HPV or iii) not measuring the outcomes of interest as dependent variables. Using Scopus, I carried out forward citation searches for all papers obtained for full-text review and included those published up to August 2015. Dr Laura Marlow confirmed the eligibility of articles found through forward citation and reference searching. A summary of the data from all full-text articles was extracted (Table 4.1 and Table 4.3) into Microsoft Excel.

4.2.4 Quality assessment

The quality of the studies was assessed using an amended version of NICE quality appraisal checklist for quantitative and qualitative studies (National Institute for Care and Excellence, 2012) (Appendix 4.3 and 4.4). These checklists were selected for use in this review due to there being both a quantitative and qualitative checklist available and included items which fitted with the designs of these studies. Some of the items that were not relevant to the design were removed from the checklists. These checklists considered a range of factors which included whether the source population was well described, whether the outcome measures were reliable and relevant, whether the analytical methods were appropriate and whether the findings could be generalised to the source population. I conducted the quality assessment on all of the studies and Dr Laura Marlow assessed a random ten per cent selection.

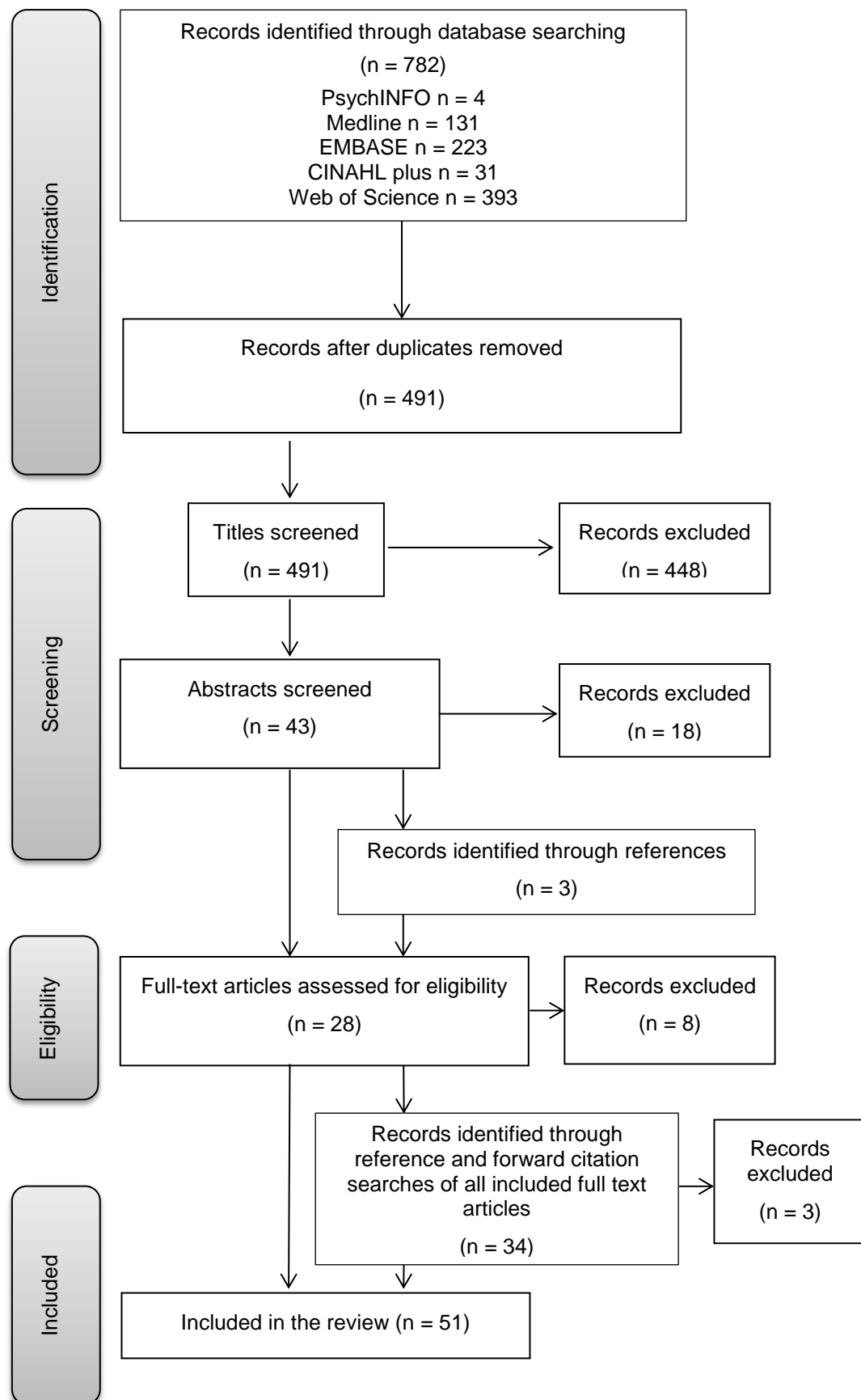


Figure 4.1: Flow diagram of study selection adapted from Moher et al (2009)

4.2.5 Analysis

Data from all included articles were recorded using a data extraction form. The data extraction form was developed for extracting the key sections of data from the articles and for assessing the quality of the studies. I developed a data extraction forms which used for both the articles measuring psychosocial outcomes and for the articles measuring knowledge (Appendix 4.5). The data extraction form was first tested with two articles from each domain and was deemed acceptable. Results from articles measuring psychosocial outcomes and knowledge are reported descriptively with comparisons drawn where appropriate. Qualitative findings are described separately.

4.3 Results

4.3.1 Search results

The initial search returned 782 articles, which was reduced to 491 after the removal of duplicates. 448 were excluded on the basis of their title, leaving 43 abstracts to be reviewed. Once the articles had been screened by title and abstract, 25 were obtained for full-text review. An additional 37 articles were included after searching the reference lists, relevant review papers found through the search and searching forward citations of those already obtained for full-text review. Eleven articles were excluded during full-text review, leaving 51 papers in the final analysis. Figure 4.1 shows the study selection process. My supervisors (Dr Jo Waller and Dr Laura Marlow) and I agreed on the final papers included in the review.

4.3.2 Studies assessing the psychosocial impact of HPV-related head and neck cancer

Ten of the studies measured psychosocial outcomes (Table 4.1) (Baxi et al., 2012; Broglie et al., 2013; Durmus et al., 2014; Dziegielewski et al., 2013; Hess et al., 2014; Marcellusi et al., 2014; Maxwell et al., 2013; Milbury et al., 2013; Sharma et al., 2012; Vainshtein et al., 2015). Of these, eight were conducted in the United States of America (USA) (Baxi et al., 2012; Durmus et al., 2014; Dziegielewski et al., 2013; Hess et al., 2014; Maxwell et al., 2013; Milbury et al., 2013; Sharma et al., 2012; Vainshtein et al., 2015), one was conducted in Switzerland (Broglie et al., 2013) and one in Italy (Marcellusi et al., 2014). Quantitative studies used survey based methods (Broglie et al., 2013; Durmus et al., 2014; Dziegielewski et al., 2013; Marcellusi et al.,

2014; Maxwell et al., 2013; Milbury et al., 2013; Sharma et al., 2012; Vainshtein et al., 2015) and one conducted an audit on medical records (Hess et al., 2014). One article collected qualitative data from individual interviews (Baxi et al., 2012). All articles were published between 2012 and 2014. All studies reported patients' HPV status, six of these were clinically verified and four were taken from patients' medical records. In some studies, p16 expression was used as a marker of HPV status, but for simplicity I refer to patients as HPV-positive throughout the review.

The psychosocial impact of HPV-related HNC was measured in patients at different time points in their care continuum from newly diagnosed (Broglie et al., 2013; Dziegielewski et al., 2013; Maxwell et al., 2013; Milbury et al., 2013; Sharma et al., 2012) to up to 5 year post treatment completion (Baxi et al., 2012).

Table 4.1: Psychosocial studies included in systematic review

Reference Country	Sample	HPV/p16 positive	Study Design	Outcomes/measures	Relevant Findings
Baxi et al., 2012 USA	10 male survivors of HPV-OSCC between 1 and 5 years treatment completion	100% (HPV+)	Qualitative semi-structured interviews	Exploring the communication, comprehension and psychological impact of a diagnosis of HPV- related oropharyngeal cancer	<ul style="list-style-type: none"> - 3/10 felt a sense of stigma or embarrassment associated with their diagnosis - The cancer itself occasionally or always overshadowed the impact of HPV - 4/10 were concerned with potentially infecting a partner with HPV and one expressed concerns about re-infection - Survivors understood and were encouraged by positive prognostic implications of an HPV diagnosis
Broglie et al., 2013 Switzerland	98 survivors of oropharyngeal cancer a median of 67 months post treatment	63.9% (p16+)	Follow-up survey (postal)	Quality of life: EORTC QLQ-C30 and EORTC QLQ-H&N35	<ul style="list-style-type: none"> - p16- patients had significantly lower scores on physical and role functions and had more complaints about feeling ill and pain than p16+ patients
Durmus et al., 2014 USA	22 patients at first head and neck cancer clinic visit; 2 females, 20 males	80.9% (HPV+) 95.2% (p16+)	Longitudinal study: baseline (pre- operatively), 3 weeks, 3 months, 6 months and 12 months	Quality of life: Head and Neck Cancer Inventory	<ul style="list-style-type: none"> - Speech, eating, aesthetics and social disruption scores at 3 weeks, 3 and 6 months were significantly lower than at baseline - Overall QOL still significantly lower than pre-operative levels at 1 year - Significant declines in overall QOL at 3 months compared with 3 weeks - No significant impact on QOL outcomes by HPV status (HPV+ compared to HPV-)

HPV, human papillomavirus; HNSCC, head and neck squamous cell carcinoma; EORTC, European Organisation for Research and Treatment of Cancer; UWQOL, University of Washington Quality of Life; HNQOL, Head and Neck Quality of Life; SF-36, Short Form 36; OSCC, Oropharyngeal squamous cell carcinoma.

Table 4.1: Psychosocial studies included in systematic review (contd.)

Reference Country	Sample	HPV/p16 positive	Study Design	Outcomes/measures	Relevant Findings
Dziegielewski et al., 2013 USA	87 patients at first new patient referral visit: 81 included in analysis (71 tested for HPV)	72% (HPV+) 85% (p16+)	Prospective cohort study	Quality of life: Head and Neck Cancer inventory	<ul style="list-style-type: none"> - All health-related QOL scores declined at 3 weeks; social and overall scores continued to drop and were the lowest at 3 months - Social and overall scores demonstrated at 12 months greatest recovery significantly from baseline - No differences between HPV+ and HPV- patients on any of the QOL domains at 12 months
Hess et al., 2014 USA	162 medical records - patients with locally advanced OSCC, known p16 status and treated by chemoradiation or primary surgery followed by adjuvant radiation therapy; 142 men, 20 women	69% (p16+)	Audit of medical records	Prevalence of anxiety disorder and major depression in patients with HPV+ and HPV- tumours	<ul style="list-style-type: none"> - No significant differences between HPV+ and HPV- patients for rates of major depression or anxiety disorder - Higher prevalence of anxiety in HPV- patients

HPV, human papillomavirus; HNSCC, head and neck squamous cell carcinoma; EORTC, European Organisation for Research and Treatment of Cancer; UWQOL, University of Washington Quality of Life; HNQL, Head and Neck Quality of Life; SF-36, Short Form 36; OSCC, Oropharyngeal squamous cell carcinoma.

Table 4.1: Psychosocial studies included in systematic review (contd.)

Reference Country	Sample	HPV/p16 positive	Study Design	Outcomes/measures	Relevant Findings
Milbury et al., 2013 USA	62 newly diagnosed HPV+ patients initiating radiotherapy	98% (p16+) 89% (HPV+)	Cross-sectional survey	Self-reported: <ul style="list-style-type: none"> - Feelings of keeping their HPV a secret from others - Disclosure of HPV to current sexual partner - Whether HPV increased partner's risk of developing cancer - Whether they talked to partner about likelihood of transmission - How much knowledge of HPV as a cause had impacted their relationship - Distress - Self-blame 	<ul style="list-style-type: none"> - Approx. 30% showed marked distress - Distress levels were moderate - Patients reported low levels of behavioural self-blame - Blame and distress were significantly correlated - No significant differences regarding distress and self-blame in those self-declaring as HPV+ compared to those who did not or were unsure - 14% intended to keep it a secret from others and 3% did not tell their partner – reasons included embarrassment, stigma, and belief it is no-one else's business - 41% said they had not discussed concerns regarding potential viral transmission to their partner - 8% thought their HPV had entirely increased their partners risk for developing cancer, 42% somewhat and 29% said it did not - 80% reported that the diagnosis had no negative impact, 14% reported a somewhat negative impact, 6% reported a completely negative impact on relationships

HPV, human papillomavirus; HNSCC, head and neck squamous cell carcinoma; EORTC, European Organisation for Research and Treatment of Cancer; UWQOL, University of Washington Quality of Life; HNQOL, Head and Neck Quality of Life; SF-36, Short Form 36; OSCC, Oropharyngeal squamous cell carcinoma.

Table 4.1: Psychosocial studies included in systematic review (contd.)

Reference Country	Sample	HPV/p16 positive	Study Design	Outcomes/measures	Relevant Findings
Sharma et al., 2012 USA	228 patients diagnosed with primary OSCC between 2003 and 2010 Group 1: (n=162) HPV- and low-risk HPV Group 2: (n=66) High-risk HPV+	29% (HPV+)	Longitudinal study: pre- treatment, immediate post-treatment and one year post-treatment	Quality of life: UWQOL	<ul style="list-style-type: none"> - Pre-treatment QOL was significantly higher in patients who were HPV+ - Immediate post treatment scores were lower in HPV+ patients - Post treatment scores were similar between the two groups - Group 2 had a significantly larger decrease in QOL scores from pre-treatment to immediate post-treatment compared to group 1 - The change in QOL scores from post-treatment to 1 year post treatment was similar between the groups - HPV status was associated with pre-treatment QOL and a change in QOL from pre-treatment to immediate post treatment - Patients in group 2 did not have better 1 year QOL compared with group 1

HPV, human papillomavirus; HNSCC, head and neck squamous cell carcinoma; EORTC, European Organisation for Research and Treatment of Cancer; UWQOL, University of Washington Quality of Life; HNQOL, Head and Neck Quality of Life; SF-36, Short Form 36; OSCC, Oropharyngeal squamous cell carcinoma.

Table 4.1: Psychosocial studies included in systematic review (contd.)

Reference Country	Sample	HPV/p16 positive	Study Design	Outcomes/measures	Relevant Findings
Vainshtein et al., 2015 USA	40 head and neck cancer survivors >2 years after treatment: 34 men, 6 women	98% (HPV+)	Follow-up survey (postal)	Health-related quality of life: HNQOL, UWQOL, SF-36	<ul style="list-style-type: none"> - Global HNQOL remained stable compared to 2 year assessments for HNQOL and UWQOL - Clinically meaningful declines in global HRQOL from 2 year assessment were reported by 8% of patients by HNQOL and 14% of patients by UWQOL - 8% on HNQOL and 11% on UWQOL reported meaningful improvements in global HNQOL - 84% and 75% of patients reported stable global HRQOL compared with 2 years by HNQOL and UWQOL - Overall physical and mental health mean scores on the SF-36 were comparable to US population norms in each HRQOL domain - Overall cohort experienced stable HNQOL scores and statistically worse UWQOL score compared to pre-treatment - Clinically meaningful declines were found in global HRQOL from pre-treatment by 8% on HNQOL and 30% on UWQOL
HPV, human papillomavirus; HNSCC, head and neck squamous cell carcinoma; EORTC, European Organisation for Research and Treatment of Cancer; UWQOL, University of Washington Quality of Life; HNQOL, Head and Neck Quality of Life; SF-36, Short Form 36; OSCC, Oropharyngeal squamous cell carcinoma.					

4.3.2.1 Psychological measures used

QOL was the main outcome measure used in seven studies and was measured using a number of different tools. Six of these studies measuring QOL used at least one HNC specific measure (Table 4.2). Two studies used the Head and Neck Cancer Inventory (HNCI) (Durmus et al., 2014; Dziegielewski et al., 2013), which is a validated 30-item survey measuring patient-reported QOL status in speech, eating, aesthetics and social disruption. QOL measures previously discussed in chapter 2 were also used. Three studies used the UWQOL (Maxwell et al., 2013; Sharma et al., 2012; Vainshtein et al., 2015), which is a validated HNC-specific QOL questionnaire including 12 domains, with two subscales of physical and social-emotional functioning. One study used the European Organisation for Research and Treatment of Cancer (EORTC) HNC specific version (QLQ-H&N35) (Broglie et al., 2013), which includes seven scales measuring pain, swallowing, senses, speech, social eating, social contact and sexuality. One study used the Head and Neck Quality of Life (HNQOL) (Vainshtein et al., 2015), which measures the four domains of eating, communication, pain, and emotion.

Generic QOL measures were used in three of these studies and included the Medical Outcome Study Short Form 36 (SF-36) which is a 36-item generic measure of health status split into 10 domains (Vainshtein et al., 2015), the EQ-5D (Marcellusi et al., 2014), which has five dimensions of measuring QOL, and the EORTC general core questionnaire (QLQ-C30) measuring activity, physical and social functioning (Broglie et al., 2013). Other psychosocial measures used were the National Comprehensive Cancer Network's distress thermometer, which uses a scale from 0 to 10 for patients to indicate how much distress they have been experiencing in the last week, and Glinder and Compas one-item measure of behavioural blame (Milbury et al., 2013) (i.e., "How much do you blame yourself for the kinds of things you did, that is, for any behaviors that may have led to your cancer?").

4.3.2.2 Findings of cross-sectional studies with a comparison group

One study compared QOL in HPV-positive patients and HPV-negative patients using the EORTC QLQ-C30 (Broglie et al., 2013; Table 4.2). Patients with HPV-positive tumours were found to score significantly better on physical and role functions of the scale, but there were no significant differences between the groups in the emotional, social and global health functions of

the scale (Broglie et al., 2013). The numbers in each group were small however, so the study was unlikely to have had enough power to detect differences if they were not large. In an audit of medical records, Hess and colleagues (Hess et al., 2014) found there was a higher prevalence of anxiety in HPV-negative patients compared to HPV-positive patients, but rates of major depression or anxiety disorder did not differ significantly between the HPV-positive and HPV-negative groups. Another study compared QOL scores measured using the EQ-5D between HPV-positive patients and healthy subjects attending the same clinic for nonpathological reasons, matched to patients for sex and disease proportion (Marcellusi et al., 2014). Overall QOL was significantly lower in HPV-positive patients than healthy subjects.

4.3.2.3 Findings from longitudinal studies with a comparison group

Four studies compared QOL between HPV-positive and HPV-negative patients at more than one time point (Durmus et al., 2014; Dziegielewski et al., 2013; Maxwell et al., 2013; Sharma et al., 2012). One study measuring QOL using the UWQOL (Maxwell et al., 2013), found overall QOL scores were better at each time point for HPV-positive patients than HPV-negative patients, with the differences being significant at baseline, 6 months and after 12 months. Another study measuring QOL using the UWQOL (Sharma et al., 2012) found pre-treatment QOL scores were significantly higher in HPV-positive patients compared to HPV-negative patients, lower (but not significantly) at immediate post-treatment, and similar at one year post-treatment. QOL measured using the HNCI in one study found HPV-positive patients had higher QOL at baseline, but then lower QOL at 3 weeks, 3 months and 6 months compared to HPV-negative patients (Durmus et al., 2014). Another study using the HNCI found HPV status was not associated with QOL outcomes at 12 months (Dziegielewski et al., 2013). Using data from the whole sample, clinically meaningful declines were found from baseline to 12 months in speech function, aesthetic attitude, eating function and attitude (Dziegielewski et al., 2013).

Overall, these longitudinal studies found inconsistent results when comparing QOL in HPV-positive patients and HPV-negative patients. Some reported HPV-positive patients with a combination of both higher and lower QOL scores than HPV-negative patients depending on the time points ($n=3$), with differences only significant when the QOL scores were higher in HPV-positive patients. Others found no significant differences between the groups at any time point

(n=2). As these studies used a variety of time points at which to measure QOL after baseline and used different measures of QOL, this makes comparisons across studies difficult.

4.3.2.4 Findings from studies with HPV-positive patients only

Three studies did not include a comparison between HPV-positive patients and HPV-negative patients (Baxi et al., 2012; Milbury et al., 2013; Vainshtein et al., 2015). One study measured distress and self-blame in newly diagnosed HPV-positive patients (Milbury et al., 2013). Distress levels were found to be moderate (mean 3.38, range 0-9), with 30% showing clinically meaningful scores (scores above or equal to 4). Self-blame levels were found to be low (mean 2.27, range 1-4). The second study measured QOL using the UWQOL, HNQOL and SF-36 and found summary scores remained stable between two years and long-term follow up (median of 78 months following completion of treatment) (Vainshtein et al., 2015). Clinically meaningful (≥ 10 point change) declines in QOL measured using the UWQOL were found in 14% of patients, while 11% of patients reported clinically meaningful improvements. Summary scores on this measure between pre-treatment and long-term follow up were significantly worse. Clinically meaningful (≥ 10 point change) declines in QOL measured using the HNQOL were found in 8% of patients, with 8% of patients reporting clinically meaningful improvements. Summary scores on this measure remained stable between pre-treatment and long-term follow up. Scores on the SF-36 for long-term physical and mental health were comparable to the USA population norms (Vainshtein et al., 2015). The one qualitative study with HPV-positive HNC survivors reported that 3/10 cancer survivors felt a sense of stigma or shame associated with their diagnosis (Baxi et al., 2012). This study also found the top three emotional responses to their HPV diagnosis to be optimism (9/10), concern (8/10) and relief (7/10). Relief and optimism were responses reported as a consequence of the better prognosis for HPV-OSCC patients. Embarrassment, surprise, sadness and fear were all reported by 6/10 of the participants. Five of the eight participants who spoke about their sexual relationships, reported a decrease in intimacy with their partner, which were mostly to do with fear of transmitting HPV to their partner. Three of the participants had ceased deep-kissing or performing oral sex on their partners. All of these studies were conducted with small sample sizes, so it would be necessary to replicate these findings in larger samples to get more representative results and have the ability to draw some conclusions.

Table 4.2: Scores from psychosocial measures in HPV-related head and neck patients in 9* studies

Reference	Measure	HPV+	HPV-	Significant difference
Brogie et al., 2013	Quality of life - EORTC QLQ-C30 (median score; scale range 0-100)			
	<i>Physical</i>	100	86.67	0.001
	<i>Role</i>	100	91.67	0.03
	<i>Emotional</i>	91.67	83.33	NS
	<i>Social</i>	100	100	NS
	<i>Global Health</i>	83.33	79.17	NS
Durmus et al., 2014	Quality of life - HNCI (mean score; scale range 0-100)			
	<i>Baseline (pre-treatment)</i>	94	75	NS
	<i>3 weeks</i>	79	88	NS
	<i>3 months</i>	48	58	NS
	<i>6 months</i>	63	83	NS
	<i>12 months</i>	88	/	NS
Dziegielewska et al., 2013	Quality of life - HNCI (mean score; scale range 0-100)			
	<i>12 months</i>	75	78	NS
Maxwell et al., 2013	Quality of life – UWQOL (mean score across 12 domains; scale range 0-100)			
	<i>Baseline (pre-treatment)</i>	76	50	0.008
	<i>2 months</i>	57	51	NS
	<i>6 months</i>	67	59	0.034
	<i>12 months</i>	69	64	NS
	<i>>12 months</i>	82	65	0.013
Sharma et al., 2012	Quality of life – UWQOL (mean score across 12 domains; scale range 0-100)			
	<i>Pre treatment</i>	86	79	0.015
	<i>Immediate post treatment</i>	63	73	NS
	<i>Post treatment</i>	75	77	NS
Vainshtein et al., 2015	Quality of life – UWQOL (mean score; scale range 0-100)			
	<i>Pre-treatment</i>	10	/	
	<i>24-months</i>	15.2	/	
	<i>Long-term</i>	16.5	/	
	HNQOL (mean score; scale range 0-100)			
	<i>Pre-treatment</i>	15.1	/	
	<i>24-months</i>	9.5	/	
	<i>Long-term</i>	11.9	/	
Marcellusi et al., 2014	EQ-5D (mean utility values)			
	Women	0.7 (SD=0.2)	/	
	Men	0.8 (SD=0.2)	/	
Hess et al., 2014	Major depression	9%	10%	NS
	Anxiety disorder	6%	12%	NS
Milbury et al., 2013	Distress (mean; scale range)	3.38 (0-9)	/	
	Self-blame (mean; scale range)	2.27 (1-4)	/	

*One reference not included as used qualitative methodology (Baxi et al., 2012); NS=not significant; SD=standard deviation

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Alami, El Sabbagh, & Hamdan, 2013 Jordan	112 newly graduated medical and dental senior house officer level; 49% dental degree, 51% medical	Not reported	Cross-sectional survey (in person)	Knowledge of risk factors for oral cancer (e.g. Which of the following factors is considered an increased factor for oral cancer: Human papillomavirus as a response option)	- HPV correctly recognised as a risk factor by 34% - more dental (47% vs 21%) than medical responded correctly
Ashe, Elter, Southerland, Strauss, & Patton, 2006 USA	651 dental hygienists from North Carolina State Board of Dental Examiners	53%	Cross-sectional survey (postal)	Knowledge of risk factors for oral cancer (e.g. In the United States, which of the following factors places an individual at high risk for oral cancer? Human papilloma virus as yes/no/don't know option)	- 47.1% recognised HPV as a risk factor for oral cancer - 32% felt patients are knowledgeable about oral cancer risk factors
Boroumand, Garcia, Selwitz, & Goodman, 2008 USA	248 1st, 2nd, 3rd and 4th year dental students at University of Maryland Baltimore College of Dental Surgery	59.6%	Cross-sectional survey (in person and postal)	Knowledge of oral cancer risk factors	- 30.8% 1st year, 89.1% 2nd year, 78.1% 3rd year, 81.8% 4th year knew HPV a risk factor for oral cancer

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Brewer, Ng, McRee, & Reiter, 2010 ³ USA	609 men aged 18-59 years from population- based panel of US households: Men's Health Study	70%	Cross-sectional survey (online)	Awareness and knowledge Perceived knowledge Beliefs about causes of HPV-related disease	<ul style="list-style-type: none"> - More men knew HPV can cause genital warts (41%) than oral cancer (23%) - 90% said knew little or nothing at all about oral cancer - 43% recognised infection with a virus as a potential cause of oral cancer (less than for anal cancer or genital warts) - Few believed sexual behaviours increases risk of oral cancer (23% having sex; 26% high number of sexual partners)
Cannick, Horowitz, Drury, Reed, & Day, 2005 USA	163 dental students, Medical University of South Carolina	79.1%	Cross-sectional survey (in person)	Knowledge of risk factors for HPV	<ul style="list-style-type: none"> - 79.8% correctly recognised HPV as a risk factor
Clovis, Horowitz, & Poel, 2002 Canada	670 dentists, British Columbia and Nova Scotia	55.2%	Cross-sectional survey (postal)	Knowledge of risk factors for HPV	<ul style="list-style-type: none"> - 53.1% correctly recognised human papillomavirus as a risk factor for oral cancer
Colón-López et al., 2012 Puerto Rico	206 men in sexually transmitted disease clinic	Not reported	Cross-sectional survey (in person)	HPV awareness, HPV knowledge (e.g. HPV is associated with oral cancer)	<ul style="list-style-type: none"> - 27.4% recognised HPV infection has a role in oral cancer (HPV is associated with oral cancer)

³ These four papers use data from the same study

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Daley et al., 2011 USA	17 dentists in 2 focus groups, 21 dental hygienists in 2 focus groups	Not reported	Qualitative focus groups	Assess awareness of oral health providers regarding the HPV-oral cancer link Elicit attitudes and perceived role in screening for HPV-oral cancer lesions and discussing HPV as a contributing factor for oral cancer	<ul style="list-style-type: none"> - Participants ranged from a complete lack of knowledge to understanding some intricacies of the HPV-oral cancer link - Shifts in dentistry practice were seen as a result of the HPV-oral cancer link and there was a desire for additional guidance from professional organisation on ways to manage screening for HPV-related oral cancer - Discomfort was expressed in discussing the HPV-oral cancer link with patients, with concerns about the appropriateness of HPV-oral cancer discussions with patients due to confidentiality and gender roles - Responses varied as to whether it was their role to discuss with patients
Decuseara, MacCarthy, & Menezes, 2011 Ireland	254 dentists	Not reported	Cross-sectional survey (online)	Knowledge of oral cancer risk factors	<ul style="list-style-type: none"> - 60% knew human papillomavirus is a risk factor for oral cancer
Dodd, Riley, & Logan, 2012 USA	93 community members	32%	Cross-sectional survey (telephone)	Knowledge of oral cancer risk factors	<ul style="list-style-type: none"> - 34% knew having human papillomavirus 'increases the risk of getting mouth or throat cancer'

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Dumitrescu, Ibric, & Ibric-Cioranu, 2014 Romania	192 1st-6th year dental students; 139 female, 53 male	100%	Cross-sectional survey (in person)	Oral cancer risk factors	- Almost 54% recognised HPV as a risk factor for oral cancer
Dwojak et al., 2015 USA	205 American Indian community members recruited via two community events; 70% female	Not reported	Cross-sectional survey (in person)	Knowledge of the risk factors of head and neck cancer including HPV (e.g. Do you think that HPV can cause head and neck cancer?)	- 32% had heard of head and neck cancer - 23% identified having multiple sexual partners as a risk factor - 36% thought HPV related to head and neck cancer
Hassona, Scully, Shahin, Maayta, & Sawair, 2015 Jordan	330 primary healthcare professionals	87%	Cross-sectional survey (face-to-face interview)	Knowledge of oral cancer risk factors	- 43.3% recognised human papillomavirus as a risk factor
Hertrampf, Wiltfang, Koller, Klosa, & Wenz, 2010 ⁴ Germany	306 dentists in Schleswig-Holstein	14%	Cross-sectional survey (postal)	Knowledge of risk factors for oral cancer (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- 57.8% recognised human papillomavirus as a risk factor

⁴ These two papers include data from the same study

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Hertrampf, Wenz, Koller, Grund, & Wiltfang, 2011 Germany	394 dentists in Schleswig-Holstein	17%	Cross-sectional survey (postal)	Knowledge of risk factors for oral cancer (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- 61.2% recognised human papillomavirus as a risk factor; 63.4% in those participating at re-evaluation and attending a continuing education course on oral cancer
Hertrampf, Wenz, Koller, & Wiltfang, 2012 ³ Germany	306 dentists in Schleswig-Holstein; 1000 members of the public	14%	Cross-sectional survey (postal and telephone)	Knowledge of risk factors for oral cancer (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- 57.8% dentists recognised human papillomavirus as a risk factor; 29% public
Hertrampf et al., 2014 Germany	388 medical practitioners in Schleswig-Holstein	13%	Cross-sectional survey (postal)	Knowledge of risk factors for oral cancer (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- Human papillomavirus recognised as risk factor by 70% otorhinolaryngology, 54% GPs, 50% Internal medicine (continuing education for general medical care), 51% internal medicine, 82% dermatologists
Gilbert, Brewer, Reiter, Ng, & Smith, 2011 ² USA	609 men: 312 gay and bisexual, 296 heterosexual	70%	Cross-sectional survey (online)	Perceived knowledge of HPV-related disease	- 21% of heterosexual men and 25% of gay/bisexual men knew HPV can cause oral cancer

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Jaber, Shaban, & Hariri, 2012 Saudi Arabia	236 healthcare professionals	Not reported	Cross-sectional survey (in person)	Knowledge of risk factors for oral cancer	- 39.1% knew human papillomavirus was a risk factor for oral cancer
Kujan, Abuderman, Azzegahiby, Alenzi, & Idrees, 2013 Saudi Arabia	167 undergraduate medical students (all students in year 4-6)	100%	Cross-sectional survey (in person)	Knowledge of risk factors for oral cancer (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- 65.7% overall recognised human papillomavirus as high-risk factor of oral cancer Men 4th yr 19%; 5th yr 17%, 6th yr 16% Female 4th yr 5%, 5th yr 4%, 6th yr 4%
Kujan et al., 2014 Saudi Arabia	479 undergraduate dental students (all students in year 4-6)	87.1%	Cross-sectional survey (in person)	Knowledge of risk factors for oral cancer	- 83.7% recognised human papillomavirus as placing someone at high risk for oral cancer Men 4th yr 10%; 5th yr 15%; 6th yr 15% Female 4th yr 12%; 5th yr 15%; 6th yr 16%
Little, Ogilvie, & Mirwaldt, 2015 Canada	176 males at postsecondary institutions in Greater Vancouver	Not reported	Cross-sectional survey (in person)	Knowledge of HPV	- 32.9% knew 'HPV infections can cause oral cancers' and 24.2% knew 'HPV infections can cause pharyngeal (throat) cancers'

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Luryi et al., 2014 USA	2126 USA adults from Harris Interactive online panel	Not reported	Cross-sectional survey (online)	Awareness (e.g. Did you know that the virus HPV (human papillomavirus) that causes cervical cancer is also associated with throat cancer?) Knowledge (e.g. How knowledgeable are you about oral, head, and neck cancer?)	<ul style="list-style-type: none"> - 66% considered themselves not very or not at all knowledgeable about head and neck cancer - Knowledge of HPV as a risk factor in 0.8% - 12.8% were aware of this association when specifically queried about the association between HPV and throat cancer - Respondents with a college or university degree were more likely to associate HPV with throat cancer (14.8% vs 10%) - Older age was associated with less knowledge of HPV as a risk factor
Malloy, Ellender, Goldenberg, & Dolan, 2013 USA	297 American Head and Neck Society head and neck surgeons	27.5%	Cross-sectional survey (online)	Assess clinical practices Assess attitudes Assess knowledge regarding HPV-related cancer of the head and neck	<ul style="list-style-type: none"> - 90.9% said they discuss HPV as a risk factor with patients - Respondents specifically with daughters - about 85% discussed HPV as a risk factor - Scored very well on knowledge items of HPV - in 5 out of 7, over 92% of responses were correct
Maybury, Horowitz, Yan, Green, & Wang, 2012 USA	619 dentists in Maryland	53.6%	Cross-sectional survey (postal)	Knowledge of risk factors for oral cancer	<ul style="list-style-type: none"> - 88% knew HPV a risk factor for oral cancer

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Osazuwa-Peters et al., 2015 USA	303 Drag racers (28.3%) and fans (70%), vendors (1.7%) attending annual United Black Drag Racers drag racing event in St Louis	Not reported	Cross-sectional survey (in person)	Knowledge of HPV and HNC (e.g. Please indicate whether you think that each of these things may or may not increase a person's chance of getting head and neck cancer: Human papillomavirus infection; Certain types of HPV can lead to oral cancer: True)	<ul style="list-style-type: none"> - 29.9% knew HPV definitely increases the risk of developing oral, HNC - M 49%; F 62.6%
Patton, Elter, Southerland, & Strauss, 2005 USA	584 licensed dentists in North Carolina	52%	Cross-sectional survey (postal)	Knowledge of oral cancer risk factors (e.g. In the United States, which of the following factors places an individual at high risk for oral cancer?)	<ul style="list-style-type: none"> - 60% recognised human papillomavirus as a risk factor for oral cancer
Pelullo, Di Giuseppe, & Angelillo, 2012 Italy	1000 lesbian, gay and bisexual men and women	86.8%	Cross-sectional survey (in person)	Know that HPV can cause oropharyngeal cancer	<ul style="list-style-type: none"> - 47% gay men, 44% lesbians, 31% bisexual men and 35% of bisexual women knew oral cancer is an HPV related disease - The vast majority knew unprotected sex was the main risk factor - 60.6% had heard of HPV
Posorski, Boyd, Giblin, & Welch, 2014 USA	62 senior citizens	66%	Cross-sectional survey (in person)	Knowledge of risk factors for oral cancer	<ul style="list-style-type: none"> - 29.5% knew infection with HPV was a contributing factor for oral cancer

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Reed, Duffy, Walters, & Day, 2005 USA	450 medical students, South Carolina	78.8%	Cross-sectional survey (in person)	Knowledge of risk factors for oral cancer	- 61.4% overall knew human papillomavirus associated with an increased risk for oral cancer; 33.7% 1st yr; 58.7% 2nd yr; 80.8% 3rd yr; 64.7% 4th yr
Reed et al., 2010 USA	269 dentists, 19 oral surgeons, 221 physicians	57% dentists 76% oral surgeons 45% physicians	Cross-sectional survey (postal)	Knowledge of risk factors for oral cancer (e.g. Rank (high, medium, low) the association of known high-risk factors (human papillomavirus) with oral cancer)	- Human papillomavirus ranked as high risk by 26% dentists, 37% physicians; medium risk by 49% dentists and 45% physicians; low risk by 26% dentists, 37% physicians
Reiter, Brewer, & Smith, 2010 ² USA	609 men aged 18-59 from national panel of US households	70%	Cross-sectional survey (online)	Knowledge of HPV	- 21% of those having heard of HPV responded yes to HPV can cause oral cancer
Reiter, Brewer, McRee, Gilbert, & Smith, 2010 ² USA	306 men self-identified as gay or bisexual aged 18-59 from national panel of US households	70%	Cross-sectional survey (online)	Knowledge of HPV	- 25% of those having heard of HPV responded yes to HPV can cause oral cancer
Riley et al., 2013 USA	2393 general population from rural areas	Not reported	Cross-sectional survey (telephone)	Knowledge of risk factors for mouth and throat cancer	- 40.2% Having human papillomavirus 'Yes-it increases the risk of getting mouth or throat cancer'
Saleh et al., 2014 Malaysia	362 dentists	41.7%	Cross-sectional survey (in person)	Knowledge of risk factors for oral cancer	- 67.2% knew human papillomavirus is a risk factor for oral cancer

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
Schuler & Coyne-Beasley, 2015 USA	267 parents of sons eligible to receive HPV vaccination	Not reported	Cross-sectional survey (in person)	Parent's knowledge of HPV in oropharyngeal cancer	- 18% knew role of HPV in oropharyngeal cancer
Sitheeque, Ahmad, & Saini, 2014 Malaysia	147 final year medical and dental undergraduates of Universiti Sains Malaysia	73.5%	Cross-sectional survey (in person)	Aetiology of oral cancer	- 59.6% of medical students and 75.6% of dental students knew or role of human papillomavirus in aetiology of oral cancer (not stat sig difference)
Sledge, 2015 USA	68 male African American college students, St Louis	Not reported	Cross-sectional survey (online)	Knowledge of HPV	- 60.2% knew HPV can cause oral cancer in men; 61.7% knew HPV can cause oral cancer in women
Trad, Reardon, & Caraveo, 2013 USA	361 freshman students at Texas State University	10.7%	Cross-sectional survey (online)	Knowledge: - HPV can be contracted through oral sex - HPV has a strong correlation with oropharyngeal cancer - HPV is associated with some head and neck cancers	- 71.5% knew HPV could be contracted through oral sex - 51.6% knew of an association between HPV and oropharyngeal cancer - 18.2% knew HPV is associated with some head and neck cancers
Wheldon, Daley, Buhi, Nyitray, & Giuliano, 2011 USA	179 men self-identified as gay and bisexual	Not reported	Cross-sectional survey (online)	Knowledge of HPV	- 25% of those having heard of HPV responded yes to HPV can cause oral cancer

Table 4.3: Included studies measuring knowledge of HPV and head and neck cancer (contd.)

Reference Country	Sample	Response rate	Study Design	Outcomes/measures	Relevant Findings
White, Creighton Jr, Wise, & Hapner, 2014 USA	491 NASCAR fans, 158 medical students, 186 undergraduate students	Not reported	Cross-sectional survey (in person)	Awareness of relationship between HPV and HNC (e.g. How much do you agree that HPV increases the risk of HNC?)	- Mean score: Medical students 2.84; Undergraduates 2.31; NASCAR 2.63

NASCAR=National Association for Stock Car Auto Racing

4.3.3 Studies assessing knowledge of HPV-related head and neck cancer

Forty one papers from 37 studies assessed knowledge about HPV and HNC (Table 4.3). Over half (n=24) were conducted in the USA, with others from Germany (n=4), Saudi Arabia (n=3), Canada (n=2), Malaysia (n=2), Jordan (n=2), Italy (n=1), Puerto Rico (n=1), Romania (n=1) and Ireland (n=1). All were published between 2002 and 2015. Quantitative studies (n=40) used survey-based data collection methods and one qualitative study collected data using focus groups (Daley et al., 2011).

Studies assessing knowledge of HPV and HNC included samples of dental students (Boroumand et al., 2008; Cannick et al., 2005; Dumitrescu et al., 2014; Kujan et al., 2014; Sitheeque et al., 2014), medical students (Kujan et al., 2013; Reed et al., 2005; Sitheeque et al., 2014; White et al., 2014), general undergraduate students (Little et al., 2015; Sledge, 2015; Trad et al., 2013; White et al., 2014), oral health providers (dentists and dental hygienists; Ashe et al., 2006; Clovis et al., 2002; Daley et al., 2011; Decuseara et al., 2011; Hertrampf et al., 2011, 2012, 2010; Maybury et al., 2012; Patton et al., 2005; Reed et al., 2010; Saleh et al., 2014), head and neck surgeons (Malloy et al., 2013), healthcare professionals (Hassona et al., 2015; Hertrampf et al., 2014; Jaber et al., 2012; Reed et al., 2010), a population-based sample of USA men (Brewer et al., 2010; Reiter, Brewer, & Smith, 2010) and a population-based sample of USA adults (Dodd et al., 2012; Luryi et al., 2014; Posorski et al., 2014; Riley et al., 2013; Schuler & Coyne-Beasley, 2015). Some specific sample populations were included such as American Indian community members (Dwojak et al., 2015), bisexual and homosexual populations (Gilbert et al., 2011; Pelullo et al., 2012; Reiter, Brewer, McRee, et al., 2010; Wheldon et al., 2011) and National Association for Stock Car Auto Racing (NASCAR) fans (White et al., 2014).

Knowledge of the association between HPV and HNC varied across study populations and the questions asked (Table 4.4). All the questions involved recognition of HPV as either a cause or risk factor for oral cancer, with no studies requiring participants to recall HPV as a risk factor for oral cancer. For example, Hertrampf and colleagues (Hertrampf et al., 2014, 2011, 2012, 2010) asked 'Which of the following factors places an individual at high risk for oral cancers?' with human papillomavirus listed as a response option, and Colon-Lopez and colleagues (Colón-López et al., 2012) asked participants to respond 'true' or 'false' to the statement 'HPV is

associated with oral cancer'. As the measures used different wording to test knowledge in their sample populations, it is difficult to compare directly across each study. Table 4.4 has accumulated these results into meaningful groups to allow some comparisons to be made.

Knowledge of HPV as a risk factor for oral cancer ranged from 26% to 91% in medical or dental professional samples (Alami et al., 2013; Ashe et al., 2006; Clovis et al., 2002; Decuseara et al., 2011; Hassona et al., 2015; Hertrampf et al., 2014, 2011, 2012, 2010; Jaber et al., 2012; Malloy et al., 2013; Maybury et al., 2012; Patton et al., 2005; Reed et al., 2010) compared to between 1% and 44% in samples of members of the general population (Brewer et al., 2010; Colón-López et al., 2012; Dodd et al., 2012; Dwojak et al., 2015; Gilbert et al., 2011; Hertrampf et al., 2012; Luryi et al., 2014; Osazuwa-Peters et al., 2015; Pelullo et al., 2012; Posorski et al., 2014; Reiter, Brewer, McRee, et al., 2010; Reiter, Brewer, & Smith, 2010; Riley et al., 2013; Schuler & Coyne-Beasley, 2015; Wheldon et al., 2011). Knowledge among students ranged from 18% in general undergraduate students to 84% in undergraduate dental students (Boroumand et al., 2008; Cannick et al., 2005; Dumitrescu et al., 2014; Kujan et al., 2014, 2013; Little et al., 2015; Reed et al., 2005; Sitheeque et al., 2014; Sledge, 2015; Trad et al., 2013). Measured in focus groups with oral health providers, knowledge of the link between HPV and oral cancer was found to range from no knowledge at all, to some knowledge about the elements of the HPV and oral cancer link (Daley et al., 2011), for example, knowing some of the HPV types involved in HPV-related oral cancer.

Table 4.4: Knowledge about HPV and oral cancer reported in 35* studies

Question	%	Sample population	Reference
Heard of HPV...	59%	General population (USA)	Dwojak et al., 2014
	61%	General population (Italy)	Pelullo et al., 2012
	61%	General population men (USA)	Reiter et al., 2010a
	71%	General population men (USA)	Brewer et al., 2010
	79%	General population men (USA)	Reiter et al., 2010b
	93%	General population men (USA)	Wheldon et al., 2011
	80%	College students (Canada)	Little et al., 2015
	85%	College students (USA)	Sledge, 2015
Knew HPV was a risk factor for oral cancer...	26%	Dentists (USA)	Reed et al., 2010
	53%	Dentists (Canada)	Clovis et al., 2002
	58%	Dentists (Germany)	Hertrampf et al., 2010
	58%	Dentists (Germany)	Hertrampf et al., 2012
	60%	Dentists (USA)	Patton et al., 2005
	60%	Dentists (Ireland)	Decuseara et al., 2011
	61%	Dentists (Germany)	Hertrampf et al., 2011
	67%	Dentists (Malaysia)	Saleh et al., 2014
	88%	Dentists (USA)	Maybury et al., 2012
	47%	Dental hygienists (USA)	Ashe et al., 2006
	54%	Dental students (Romania)	Dumitrescu et al., 2014
	67%	Dental students (USA)	Boroumand et al., 2008
	80%	Dental students (USA)	Cannick et al., 2005
	84%	Dental students (Saudi Arabia)	Kujan et al., 2014
	34%	Newly graduated medical and dental personnel (Jordan)	Alami et al., 2013
	37%	Physicians (USA)	Reed et al., 2010
	39%	Healthcare professionals (Saudi Arabia)	Jaber et al., 2012
	43%	Healthcare professionals (Jordan)	Hassona et al., 2015
	50%-82%	Medical practitioners (Germany)	Hertrampf et al., 2014
	91%	Head and neck surgeons (USA)	Malloy et al., 2013
	61%	Medical students (USA)	Reed et al., 2005
	66%	Medical students (Saudi Arabia)	Kujan et al., 2013
	1%	General population (USA)	Luryi et al., 2014
	18%	General population (USA)	Schuler et al., 2015
	29%	General population (Germany)	Hertrampf et al., 2012
	30%	General population (USA)	Posorski et al., 2014

	30%	General population (USA)	Osazuwa-Peters et al., 2015)
	32%	General population (USA)	Dodd et al., 2012
	40%	General population (USA)	Riley et al., 2013
	44%	General population (Italy)	Pelullo et al., 2012
Knew HPV can cause oral cancer/head and neck cancer	13%	General population (USA)	Luryi et al., 2014
	21%	General population (USA)	Reiter et al., 2010a
	25%	General population (USA)	Reiter et al., 2010b
	36%	General population (USA)	Dwojak et al., 2014
	21-25%	General population men (USA)	Gilbert et al., 2011
	23%	General population men (USA)	Brewer et al., 2010
	27%	General population men (Puerto Rico)	Colon-Lopez et al., 2012
	39%	General population men (USA)	Wheldon et al., 2011
	18%	College students (USA)	Trad et al., 2013
	33%	College students (Canada)	Little et al., 2015
	60% in men	College students (USA)	Sledge, 2015
	62% in women	College students (USA)	Sledge, 2015
	60%	Medical Students (Malaysia)	Sitheeque et al., 2014
	76%	Dental Students (Malaysia)	Sitheeque et al., 2014
Knew HPV is strongly associated with oropharyngeal cancer			
	52%	College students (USA)	Trad et al., 2013

*Two references not included as the studies did not use comparable methodology (Daley et al., 2011; White et al., 2014)

4.3.4 Quality assessment

Psychosocial

Based on the NICE quality appraisal checklists for the quantitative studies measuring the psychosocial impact of HPV-related HNC, three studies were designed or conducted in a way that minimised bias, three studies were partly designed or conducted to minimise bias and had aspects of the study design that were unclear, and three studies were either unclear on aspects of the study reported or may not have addressed all potential sources of bias. It was not relevant to perform power calculations in the samples in these studies because the patient population for HPV-positive patients is small. The one qualitative study was clear in the purpose of the study, carried out the data collection appropriately, was clear on the context in which the study was carried out, conducted reliable analysis, provided convincing findings and drew relevant conclusions. The study was unclear about whether the relationship between the researcher and participants had been considered. The study was considered to be designed to have minimised bias.

Knowledge

For those studies assessing knowledge of the relationship between HPV and HNC, 23 studies were designed or conducted in a way that minimised bias, six studies were partly designed or conducted to minimise bias and had aspects of the study design that were unclear, and 11 studies were either unclear on aspects of the study reported or may not have addressed all potential sources of bias. The one qualitative study was clear in the purpose of the study, carried out the data collection appropriately, was clear on the context in which the study was carried out, conducted reliable analysis, provided convincing findings and drew relevant conclusions. The study was unclear about whether the relationship between the researcher and participants had been considered. The study was considered to be designed to have minimised bias.

No studies were assessed as having significant sources of bias across all aspects of the study design. The majority of studies described the source population well, used reliable and valid outcome measures, measured outcomes that were relevant and used appropriate analytical methods. Out of 25 studies in which it was relevant to perform a power calculation, only eight

did so. Many of the studies had small samples and so could not be generalised to the source population.

4.4 Discussion

This review draws together the emerging literature on the psychosocial implications of an HPV-related HNC diagnosis and awareness of the link between HPV and HNC. QOL was measured in the HPV-related HNC patient population, with inconsistent results found. QOL in those with HPV-positive cancer was found to be higher, lower or equivalent to those with HPV-negative HNC. In longitudinal studies, irrespective of the instrument used, QOL in patients was at its lowest 2-3 months after diagnosis. In some studies, QOL almost returned to pre-treatment levels after 12 months.

The UWQOL was the instrument used in three of the ten studies included in this review. This scale is specific to HNC and measures 12 different domains as single item questions. To allow for comparisons across studies, it would be ideal to have a well-validated, standardised measure that could be used in all studies. All the HNC specific QOL measures used in the studies included in the review (EORTC HNC-35, HNCI, UWQOL) measure similar constructs tapping into the physical and the psychosocial effects of HNC. The UWQOL is a simple measure and has been described as a suitable measure for use in routine clinical practice (Lowe & Rogers, 2012). Due to its ability to breakdown its 12 domains into two subscales of physical and social-emotional, this allows comparisons both across the two subscales and the individual items. Future studies measuring QOL in HNC patients in the future should use the UWQOL for both HPV-related HNCs and non-HPV related HNCs. As previously reported, it is difficult to make generalised statements about QOL that can aid in clinical decision making, due to inconsistencies in the design of QOL instruments for HNC and a lack of unified reporting standards (Ojo et al., 2012).

Use of other psychosocial measures was limited, with only two other primary research studies measuring domains other than QOL (Hess et al., 2014; Milbury et al., 2013). It is therefore difficult to draw conclusions based on the limited research which has currently been conducted around the psychosocial impact of HPV-related HNC. As discussed in chapter 2, psychosocial distress is common in HNC patients and future work is needed to explore the psychosocial

impact of a diagnosis of HPV-positive HNC for patients, as well as their partners and health professionals. One study found clinically meaningful levels of distress in 30% of patients but relatively low levels of self-blame (Milbury et al., 2013), suggesting there may be a need for interventions which may help alleviate distress levels. In the one qualitative study, a few survivors of HPV-positive HNC reported feelings of stigma and embarrassment about their diagnosis and this affected their sexual relationships (Baxi et al., 2012), consistent with findings from the cervical cancer literature (McCaffery et al., 2006).

The relationship between HPV and HNC is not well known across most populations in the studies included here. The groups who were the most knowledgeable about HPV as a risk factor for HNC were 2nd year dental students, dentists and head and neck surgeons. Awareness levels ranged across a variety of samples of the general population, dentists, students and specific sexually orientated groups, from 1% to 88%. Almost half of the studies included dentists, dental hygienists or dental students, suggesting that the role dentists have to play in HPV and HNC is being increasingly recognised, and educating them about HPV as a risk factor is important. Dentists have been shown to express enthusiasm for continued education (Alonge & Narendran, 2004; Jaber et al., 2012; Malloy et al., 2013; Maybury et al., 2012). Many studies with dentists have acknowledged their importance in early detection of oral cancers (Clovis et al., 2002; Ford & Farah, 2013; Hertrampf et al., 2010), as well as general practitioners (Carter & Ogden, 2007; Holmes, Dierks, Homer, & Potter, 2003).

All the questions used in the studies of HPV knowledge were recognition questions, where participants had HPV listed as a response option, rather than free recall where participants would have to list HPV in an open response, and so may not represent the true knowledge of participants as previous studies have found awareness to be higher in participants when responding to recognition questions when compared to recall (Low, Simon, Lyons, Romney-Alexander, & Waller, 2012; Marlow, Waller, & Wardle, 2007). One study assessing knowledge in medical practitioners in Ireland found that when asked to list the risk factors they would associate with oral cancer, HPV was not listed (Ni Riordain & McCreary, 2009). There was also no standardised question assessing knowledge of the link between HPV and HNC, some asking it as a risk factor, while others were more specific (e.g. HPV is associated with some head and neck cancers). None of the studies assessing HPV knowledge were conducted in the UK, so no conclusions can be drawn about the level of knowledge in the UK. These studies were mainly

from the USA, indicating a wide range of knowledge across different population subgroups, but that generally, there is a need for greater awareness.

As the research presented in chapter 2 demonstrated that QOL is an important outcome for HNC patients, it is appropriate that QOL is also being measured in HPV-related HNC patients. Although the results from this review are mixed for QOL, the results presented in chapter 2 illustrate the factors which are influential in affecting QOL in HNC patients. There is scope for many more of these studies to be carried out in the HPV-OSCC patient population and to examine if there are similarities or differences between the two patient populations. It is also important to examine other psychological outcomes, as patients diagnosed with HPV-OSCC may feel additional stressors compared to HPV-negative patients due to the sexually transmitted nature of HPV. HPV-OSCC patients may also feel more optimistic and feelings of relief once given the information that HPV-OSCC has a better prognosis than HPV-negative cancers.

4.5 Strengths and Limitations

Adhering to PRISMA guidelines ensured my review was carried out systematically. By including quantitative and qualitative studies in the review, I avoided exclusion of any eligible and relevant studies and the qualitative studies provided a greater depth of understanding of both the psychosocial aspects of HPV-related HNC and also the knowledge of the relationship between HPV and HNC. Great effort was taken in an attempt to include any relevant conference abstracts which had been published as papers, to ensure that the data presented in the review was as current as possible.

In terms of the limitations of this review, some eligible studies may not have been picked up in the forward citation searches if they had not yet been included on Scopus, but I am only aware of one such paper (Williams, Carr, & Goldenberg, 2015). The findings from this study concurred with the other results from my review, with 51% of military officer trainees and 25% of the general population knowing HPV was linked to oropharyngeal cancer. As a number of different instruments were used to measure QOL and at different points in the patient care continuum, it was difficult to compare across studies. Although the measures used were HNC-specific, they

were not developed for HPV and HNC patients and therefore there may be additional domains that are relevant, but have not been included in the measures.

The inclusion of the studies was also restricted to those written in English, however given the range of countries included in the knowledge section of the review, this would suggest that most of the studies in this area are written in English. There were difficulties in the interpretation of some of the studies as they asked different questions to their participants; at different points of time across the patient's disease trajectory for the psychosocial studies, and the differences in the wording of the questions for the knowledge studies. Studies which assessed knowledge through recall as opposed to recognition may not have been detected through the search terms if there was low awareness of HPV. The quality assessment of the studies was subjective and often difficult to conclude on its final rating. As a random selection were checked by Dr Laura Marlow and few disagreements were found, this strengthens the ratings given to each study. As nearly a third of studies were rated as being unclear on some aspects of the study or not addressing all potential sources of bias, it is important to take this into consideration when examining the results. I decided to include all studies to give an overview of all studies that had been conducted, but I do recognise that some of the studies may be affected by potential sources of bias.

4.6 Conclusion

This review shows a limited number of studies have measured the psychosocial impact of a diagnosis of HPV-positive HNC and those few that have, have mainly used QOL as their primary outcome measure. The previous chapters have shown that QOL is diminished in HNC patients, largely due to dysfunction and disfigurement associated with its treatment. This review provides support for those findings, but does not provide evidence of specific factors associated with the psychological impact of being diagnosed with HPV as well as HNC. Future work is therefore needed with patients to explore the impact of the diagnosis of HPV, as well as with the partners of HPV-positive HNC patients and health professionals caring for these patients. The limited knowledge of the association between HPV and HNC among the public also indicates the need for research to explore the information that these populations are receiving, particularly in the UK. None of the studies measuring knowledge of the relationship between HPV and HNC in this review were conducted in the UK and therefore we have no evidence of

knowledge in the UK. Chapter 5 explores the coverage of the relationship between HPV and HNC in the UK media and through examining the content, what information about HPV and HNC is being presented to the UK population through the media. This may be influential to how much is known about the relationship between HPV and HNC in the UK general population.

CHAPTER 5. UK MEDIA COVERAGE OF THE LINK BETWEEN HPV AND HEAD AND NECK CANCER (STUDY 2)

5.1 Introduction⁵

My systematic review (see chapter 4) showed limited knowledge of the link between HPV and head and neck cancer (HNC) among patients and the public, but greater knowledge among health professionals and medical/dental students. Prior to the start of my PhD, the American actor Michael Douglas disclosed to the media that his throat cancer was caused by HPV and as this was pertinent to my thesis, it was important to address what information about HPV-OSCC has been presented to the UK population through the media. As with the previous chapter, this chapter addresses all types of HNC and will therefore use the term HNC to encompass all anatomical sites, not just OSCC. As the media has been shown to influence patients' opinions and feelings (Passalacqua et al., 2004) and is considered a major source of health information for many (James, James, Davies, Harvey, & Tweddle, 1999), it is possible that media coverage of the link between HPV and HNC may influence public awareness and perceptions of HPV.

Prior to the introduction of the HPV vaccination in the UK in 2008, women's awareness of HPV (primarily in the context of cervical cancer) was measured to be between 24-30% in the UK (Marlow et al., 2007; Pitts & Clarke, 2002; Waller et al., 2003). The HPV vaccination attracted a lot of media attention in the UK (Forster, Wardle, Stephenson, & Waller, 2010) and knowledge of HPV appears to have increased in the UK following its introduction (Marlow et al., 2013; Sherman et al., 2015).

Human interest stories presented in the media (e.g. celebrity cancer stories) can engage the audience and can influence the extent to which further information is provided (Hilton, Hunt, Langan, Bedford, & Petticrew, 2010; Menashe, 1998). The British media is no stranger to reporting celebrities' cancer stories, most notably the stories of Jade Goody (an English reality television personality), Kylie Minogue (an Australian singer/songwriter) and Angelina Jolie (an American actress). Metcalfe and colleagues reported that following a celebrity diagnosis, an

⁵ The search for this study was conducted in August 2014. A version of this chapter has been published in *BMJ Open* (Appendix 5.1).

increased public interest in disease prevention can follow (Metcalf, Price, & Powell, 2011). This was demonstrated in the UK in the case of Jade Goody, a reality television personality who made her terminal cervical cancer diagnosis public. She died aged 27 years old and an increase in the number of women attending cervical screening was observed (Lancucki, Sasieni, & Patnick, 2012). In 2013, American actor Michael Douglas disclosed in an interview with *The Guardian* that his throat cancer was 'caused by HPV which actually comes about from cunnilingus'. This disclosure received global media attention, giving the media an opportunity to discuss the link between HPV and HNC. However, media publications are sometimes criticised for the lack of detail they provide, for example surrounding the announcement of Angelina Jolie's double mastectomy, they failed to give information about the rarity of her condition (Kamenova, Reshef, & Caulfield, 2014).

Media priming may be used to strengthen the association between a person's existing beliefs and their subsequent behaviour by making these beliefs more accessible (Fishbein & Yzer, 2003). Awareness campaigns for cancers such as breast and lung (e.g. Public Health England Be Clear on Cancer campaign) have been shown to be effective in increasing awareness of key symptoms for these cancers and increases in general practitioner attendance (Cancer Research UK, 2014). Media coverage is one route through which public understanding of health issues might be improved and may prompt help-seeking behaviour, but little is known about UK media coverage of the link between HPV and HNC. The media has been shown to be a common source of information about HPV (Pitts, Dyson, Rosenthal, & Garland, 2007) and greatly influences public opinion, and as such it is important to examine how the link between HPV and HNC is portrayed by the UK media. As the media may play an important role in fulfilling the information needs of the public, examining the content of articles will establish what information is being conveyed and how this is being communicated. The aims for this study were to answer the next two research questions of my thesis:

- 3) How frequently has the relationship between HPV and HNC received coverage in the UK media?
- 4) What information is covered in media articles covering the relationship between HPV and HNC?

The first research question demonstrates the amount of coverage that the relationship between HPV and HNC has received in the media and therefore shows how often information is communicated to the general population through the media. Future policy and research could be guided by these findings as they will provide an indication as to how frequently the general population may have read messages about HPV and HNC and what messages they may have received.

The second research question examined the content of the articles, providing an indication as to how the media may have shaped public perceptions about HPV and HNC and also by identifying the messages that the media are choosing to portray to the public. Examining these messages now, provides a basis on which we can work with the media in the future to ensure that in an era where the HPV vaccine may be introduced for boys or an oral cancer screening programme may be introduced, that the messages accompanying these are those which help to minimise any negative psychological associations. The findings from this research question could provide insight for future policy and research about which messages need to be addressed in any future publications reporting on the link between HPV and HNC. Future education strategies could also be influenced and policymakers could work together with the media in educating the public about the signs and symptoms of HNC and the relationship between HPV and HNC.

5.2 Methods

5.2.1 Reviewing media coverage

In the context of news stories about cervical cancer, HPV and the HPV vaccination, previous research reviewing the media coverage of these topics have used online databases to search for articles (Anhang, Stryker, Wright, & Goldie, 2004; Forster et al., 2010; Hilton et al., 2010). Content analysis is a popular method of analysis for studies examining media coverage of news topics (Forster et al., 2010; Hilton & Hunt, 2010; Johnson, Sionean, & Scott, 2011). Content analysis is a method that combines both qualitative and quantitative methods, allowing both the frequency of categories to be reported, as well as the content (Weber, 1990).

I used the NexisUK database (RELX Group, 2015) to search for print and online articles in the UK relating to HPV and HNC. NexisUK was chosen because it is a comprehensive online

database providing full text access to all international, national and regional news sources, and is updated daily. This database has been commonly used in previous studies analysing the content of media articles (Anhang et al., 2004; Forster et al., 2010; Johnson et al., 2011). The search was conducted on the 20th August 2014 with no date limits applied. The search terms ‘oral cancer’, ‘mouth cancer’, ‘throat cancer’, ‘oropharyngeal cancer’, and ‘head and neck cancer’ were entered into the database separately, limited to major mentions (in the headline, lead paragraph or indexing) and combined with [HPV OR human papillomavirus] within UK publications. Newswire and non-business news publications (e.g. obituaries, sports) were not searched. I reviewed the full text of each publication. Newspapers were categorised into broadsheet, middle-market and tabloids using Newsworks, which is an online marketing body for national newspapers and provides the categories of both local and national newspapers (Newsworks, 2015). Newspaper articles were categorised as “broadsheet” newspapers (more intellectual in content e.g. The Guardian, The Times), “middle-market” newspapers (coverage of entertainment and important news stories e.g. Sunday Express, London Evening Standard) and “tabloid newspapers” (reporting mostly on sensational material e.g. The Sun, Kidderminster Shuttle). Regional newspapers were categorised following discussion between Dr Alice Forster and myself. All stories reporting on the link between HPV and HNC were included. Articles were excluded if they were duplicates and/or were published in a specialist magazine or publication. Articles were excluded from the content analysis if they included less than 100 words about HPV and its link to HNC.

5.2.2 Quantitative Analysis

The frequency of reporting of the link between HPV and HNC was analysed using a frequency count. The number of articles per month reporting the link were plotted on a graph from the first publication to the most recent publication.

5.2.3 Qualitative Analysis

The headlines of all articles were analysed descriptively and the main text was analysed using content analysis. As with any qualitative analysis, content analysis can still be subjective due to its reliance on the researcher analysing the data.

The content of eligible articles was analysed using the five stages of Framework Analysis (Ritchie & Spencer, 1994). Firstly, I familiarised myself with the content by reading through all the eligible articles, making notes of recurring themes and summarising each article. Using the qualitative package NVivo 10 (QSR, 2012), I generated a list of codes and these codes were applied to the data (Appendix 5.2). The data were summarised and organised into a matrix of main themes and subthemes, with each row representing an article and each column representing a theme or subtheme. The codes were organised into a hierarchy of main themes and subthemes. Dr Alice Forster coded 20% of the articles to test inter-rater reliability. Second coding of 20% of the articles has been considered sufficient in similar studies (Johnson et al., 2011; Penta & Baban, 2014). Cohen's Kappa across all themes was 0.71 representing a substantial agreement (Cohen, 1960; Kreimer et al., 2013). Any disagreements were resolved by discussion and I coded the remaining articles.

5.3 Results

5.3.1 Article characteristics

A total of 854 UK articles were identified. Articles were excluded if they i) were duplicates (articles published around the same time, with the same number of words in the same publication and duplicating text) (n=477); ii) were published in a specialist magazine or publication (n=80); or iii) did not mention the link between HNC and HPV (n=32). Following these exclusions, 265 articles were eligible for inclusion in the quantitative analysis. An additional 153 articles were excluded from the qualitative analysis because they included fewer than 100 words about the link between HNC and HPV. These articles tended to include a sentence about the link between HPV and HNC as part of a story with a different focus; they did not have sufficient text to merit qualitative analysis. Overall 112 articles were suitable for the qualitative analysis and a couple of examples are shown in Appendix 5.3.

The newspapers with the greatest number of articles eligible for qualitative analysis were The Times (n=16), MailOnline (n=10), The Guardian (n=8) and The Independent (n=9). Broadsheet newspapers accounted for 54% of the articles, 21% were from middle-market newspapers and 25% were from tabloid newspapers. With regard to average length, broadsheet articles tended to be longer (530 words average), followed by those in middle-market newspapers (472 words

average), with tabloid newspapers having the shortest (458 words average) articles. A fairly small proportion of articles (18/112; 16%) were published in regional papers.

5.3.2 Quantitative analysis

No UK publications reported the link between HPV and HNC prior to 2001. Figure 5.1 shows the number of articles published per month mentioning the link between HPV and HNC. There was a steady number of articles reporting on the link, but for most years from 2001 to 2014, on average, fewer than two articles were published per month across the newspapers. The largest number of articles reporting on the link between HPV and HNC was seen in 2013 (112/265). Broadsheet newspapers first reported that there was a link between HPV and HNC in October 2001, followed by tabloid newspapers in February 2004 and middle-market newspapers in November 2009.

There were a few small peaks in articles published in May 2007 (6/265), with 5/6 discussing a research paper which further demonstrated the link between oral sex and throat cancer (D'Souza, Kreimer, et al., 2007) and in March 2012 (7/265) reflecting the publication of figures demonstrating a rise in mouth cancers. There was a noticeable peak in June 2013 (45/265) with 34/45 of these discussing Michael Douglas' throat cancer being caused by HPV. In November 2013 (16/265) there was another small peak with 10/16 articles reflecting on mouth cancer awareness month.

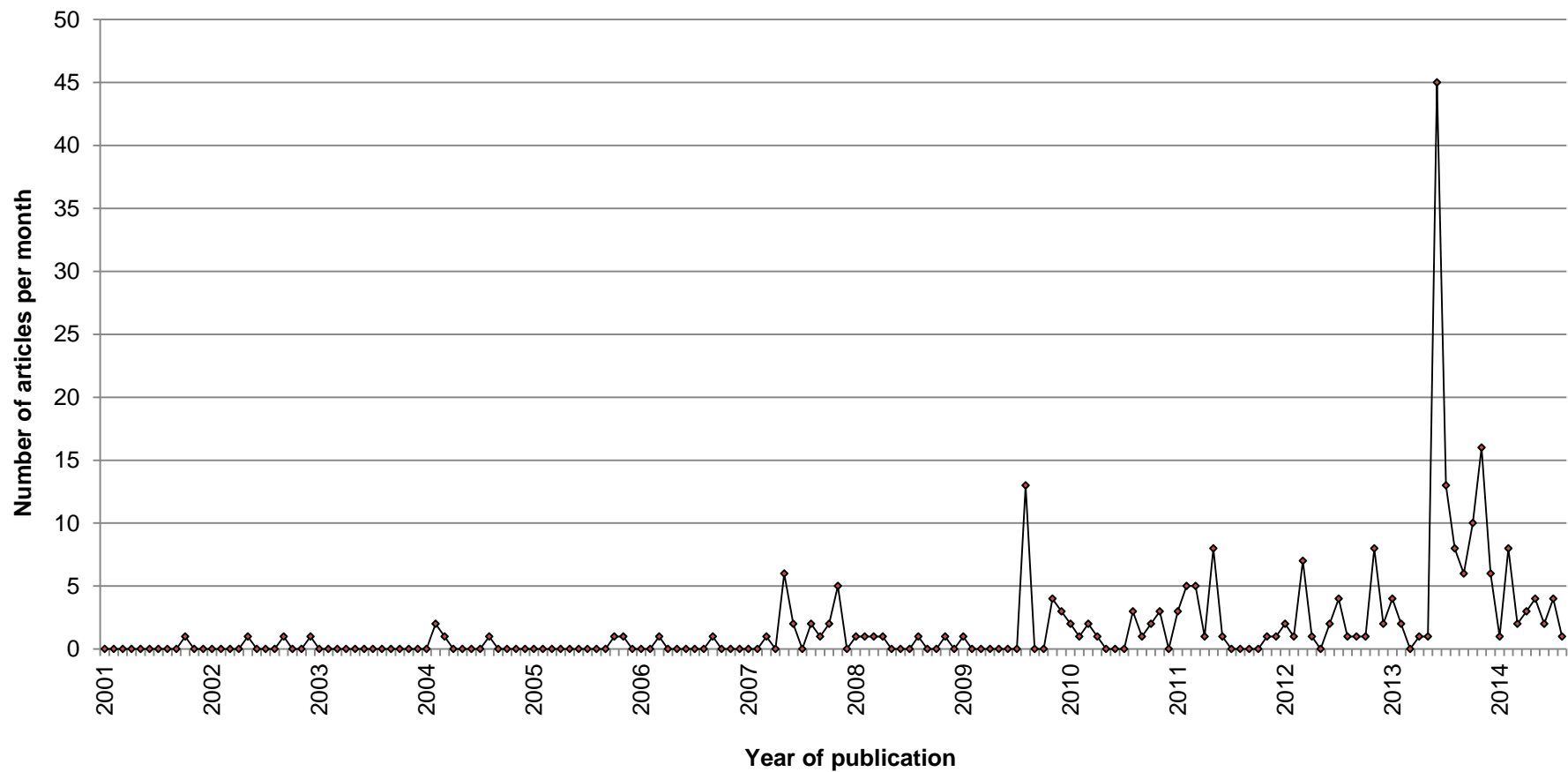


Figure 5.1: The number of UK media articles reporting on the link between HNC and HPV from 2001-2014

5.3.3 Qualitative analysis

5.3.3.1 Headlines

About one third (35/112) of the headlines mentioned oral sex (e.g. 'Oral sex can lead to mouth cancer', *Birmingham Post*, 26 February 2004) and Michael Douglas was mentioned in a quarter (n=28/112) of the headlines (e.g. 'Michael Douglas says cunnilingus gives you cancer but is he right?' *The Guardian*, 2 June 2013). 'Throat cancer' was the most frequently used term for the disease, mostly reflecting the terminology used by Douglas himself, with 'mouth cancer' and 'oral cancer' also used. Some headlines (33/112; 29%) emphasised the risk of oral sex and HPV (e.g. 'Mouth cancer rise in young people is linked to oral sex' *The Metro*, 16 March 2012), and some used the words 'risk', 'alert' and 'dangers' when referring to the link between HPV and HNC:

'Your life: Oral Sex cancer risk' (*Daily Mirror*, 28 March 2010)

'Early alert for throat cancer' (*The Times*, 22 July 2013)

'Stay alive to the dangers of mouth cancer' (*Kidderminster Shuttle*, 6 November 2010)

Others emphasised the sexual nature of the link using terms like 'sex virus', 'will oral sex ever feel safe again' and 'struck a blow for oral sex'.

5.3.3.2 Article content

Four main themes emerged from the content analysis of the reviewed articles: Michael Douglas' disclosure, the riskiness of oral sex, health information communicated about HPV, including HPV as a cause of HNC and its incidence, and the need to vaccinate boys against HPV.

Michael Douglas' disclosure

In June 2013, Michael Douglas revealed that HPV was responsible for his throat cancer and that it was transmitted through oral sex. This disclosure was more commonly reported in broadsheet newspapers (50% broadsheet vs 28% middle-market and 22% tabloid). There was a peak in the number of articles covering this link (34/112; 30%) in June 2013, including those which reported on Michael Douglas' subsequent assertion that he was talking about causes of HNC more generally, rather than being specific to him:

'Michael Douglas did not say cunnilingus was the cause of his cancer. It was discussed that oral sex is a suspected cause of certain oral cancers...but he did not say it was the specific cause of his personal cancer'. (*MailOnline*, 4 June 2013)

There were suggestions in some of the articles that Michael Douglas had raised awareness of the link between HPV and HNC and had 'broken the last taboo for men' by raising the topic of oral sex:

'Even with statements from his publicist denying he had put the blame on oral sex specifically, this genie is not going back in the bottle. And perhaps that's a good thing'. (*The Telegraph*, 4 June 2013)

There was also scepticism by one newspaper (*MailOnline*) about the motives behind Michael Douglas' disclosure, suggesting that he was 'being paid by drug companies to boost HPV vaccine sales' or that he is trying to cover up smoking as the cause of his throat cancer.

Focus was also given to Catherine Zeta-Jones (Michael Douglas' wife) suggesting Michael Douglas had contracted HPV from her:

'The actor appeared to suggest Catherine Zeta-Jones could have given him the sexually transmitted disease in a candid interview published last week'. (*Belfast Telegraph*, 7 June 2013)

One newspaper also suggested that Michael Douglas was criticised for his public honesty 'Namely, because it may embarrass his wife, Catherine Zeta-Jones' (*MailOnline*, 3 June 2013). Concern was also expressed that his wife could be at risk of cervical cancer:

'She could contract several forms of cancer, including cervical, if she contracts HPV'. (*Sunday Express*, 12 September 2010)

Riskiness of oral sex

A large number (84/112; 75%) of the articles mentioned oral sex as a cause of mouth cancer:

'Oral sex can lead to mouth cancer, according to new research'. (*Birmingham Post*, 26 February 2004)

HPV was mentioned as being transmitted through oral sex, with articles quoting Michael Douglas including the term 'cunnilingus' and stating that HPV is a sexually transmitted disease.

'Without wanting to get too specific, this particular cancer is caused by HPV, which actually comes about from cunnilingus...But yeah, it's a sexually transmitted disease that causes cancer. And if you have it, cunnilingus is also the best cure for it'. (*The Times*, 5 June 2013)

This disclosure from Michael Douglas led some articles to discuss the risk of different sexual behaviours e.g. ‘Is cunnilingus inherently riskier than fellatio?’ (*The Guardian*, 2 June 2013) with a number of these providing research findings:

‘A US study showed about 10 per cent of men aged 14 to 69 have an oral HPV infection, compared with 3.6 per cent of women. Because HPV-related oral cancer is twice as common in men as in women, cunnilingus is considered riskier than fellatio’. (*London Evening Standard*, 4 June 2013)

Some articles (14/112; 13%) expressed the belief that the rise in throat cancer was due to changes in sexual practice: ‘the rise in HPV-related throat cancer is being seen as the legacy of the sexual revolution that began in the 1960s’ (*The Independent*, 21 January 2012), with an increase in oral sex practices leading to increases in oral HPV and therefore throat cancer:

‘What is most strongly linked to oral HPV infection is the number of sexual partners someone has had in their lifetimes, in particular the number of individuals on whom they have performed oral sex’. (*The Guardian*, 21 February 2011)

The link between oral sex and mouth cancer was not as clear cut, according to Cancer Research UK quoted to have said ‘it was unclear if it was linked with oral sex’ (*The Independent*, 16 March 2012). A few (5/112; 4%) of the articles suggested that HPV transmitted through oral sex ‘could overtake tobacco and alcohol as the main risk factor in the next decade’ (*Western Morning News*, 23 November 2010).

It was also acknowledged that ‘oral sex is a topic which could not have been discussed openly even recently’ (*The Telegraph*, 4 June 2013).

One article asked ‘should oral sex be off the agenda’ (*Daily Mirror*, 28 February 2014), with other articles terming oral sex as ‘now officially life-threatening’ (*The Times*, 26 May 2007) and that HPV is a ‘devastating virus’ (*The Sun*, 13 February, 2014).

Health information

Most of the articles providing health information focused on the link between HPV and HNC. Table 5.1 shows what health information was presented in each type of publication. The different types of information are discussed.

HPV causes HNC: As mentioning the link between HPV and HNC was an inclusion criterion, all articles included this, with the majority (88/112; 79%) of the articles mentioning the link between

HPV and HNC within the first 100 words. The terms used were inconsistent, with mouth cancer, oral cancer and throat cancer used interchangeably. Some articles were more specific about the type of cancer caused:

‘These striking results provide some evidence that HPV16 infection may be a significant cause of oropharyngeal cancer’. (*The Times*, 26 July 2013)

The incidence of HNC: In total, 61/112 (54%) articles reported on the incidence of HNC, with 57/112 (51%) reporting that the number of cases was increasing. One newspaper quoted a Cancer Research UK expert as describing ‘an emerging epidemic’ [in HNC] and 5/112 (4%) quoted Cancer Research UK as linking the HPV virus to the ‘rapid rise’ [in HNC cases].

‘In Britain, the number of mouth and throat cancers have increased by 40 per cent in just a decade’. (*MailOnline*, 3 June 2013)

Table 5.1: Health themes mentioned in articles across the publication types

Health information theme	Number of articles including each theme			
	All publications (n=112)	Broadsheet (n=61)	Middle-market (n=23)	Tabloid (n=28)
HPV causes HNC	112 (100%)	61 (100%)	23 (100%)	28 (100%)
Incidence of HNC	61 (54%)	29 (48%)	13 (57%)	19 (68%)
Information about HPV				
<i>Cause of cervical cancer</i>	63 (56%)	33 (54%)	12 (52%)	18 (64%)
<i>100 variants of HPV</i>	11 (10%)	5 (8%)	3 (13%)	3 (11%)
<i>8/10 will contract HPV</i>	12 (11%)	5 (8%)	3 (13%)	4 (14%)
<i>90% will contract HPV by age 25</i>	6 (5%)	6 (10%)	0	0
Better prognosis and survival	18 (16%)	4 (7%)	10 (43%)	4 (14%)
Diagnosis and treatment	29 (26%)	10 (16%)	10 (43%)	9 (32%)
Symptoms and screening	36 (32%)	15 (25%)	10 (43%)	11 (39%)
Cited research findings	42 (38%)	23 (55%)	6 (14%)	13 (31%)

NB: Percentages are for columns

A change in the demographic characteristics of those being diagnosed with HNC was also mentioned in a number of the articles (49/112; 44%), emphasising that patients are increasingly younger, male, non-smokers and from professional backgrounds. A few (9/112; 8%) articles also suggested that there was a shift towards more women getting HNC.

Information about HPV: Over half of the articles also mentioned HPV as a cause of cervical cancer (63/112; 56%) and presented information about there being 'more than 100 variants' of HPV. In total, 19/112 (17%) articles highlighted that not all types of HPV cause cancer:

'Just a few strains cause problems, but one in particular, HPV-16, is known to cause cell changes which could develop into cancer'. (*MailOnline*, 16 March 2012)

In 30/112 (27%) articles it was mentioned that most people will be infected with HPV at some point:

'HPV is really, really common - to the point that if you're a sexually active adult, you've probably had it. By the age of 25, 90% of sexually active people will have been exposed to some form of genital HPV'. (*The Guardian*, 2 June 2013)

A total of 16/112 (14%) articles expressed the need for increased awareness of the link between HPV and HNC, for example 'few people can recognise its symptoms' (*Kidderminster Shuttle*, 6 November 2010). Nigel Carter, Chief Executive of the British Dental Health Foundation was quoted as saying, 'there is a clear gap in public knowledge about what causes mouth cancer' (*Daily Mirror*, 28 February 2014).

Better prognosis and survival: The positive prognosis and survival rates of HPV-related HNC were discussed (18/112; 16%), sometimes in the context of Michael Douglas' own survival:

'[Dr Kumar] testified to increased recovery rates among this kind of cancer sufferer. This would help explain why Douglas was given an 80% chance of survival, despite the advanced stage of his illness'. (*The Guardian*, 2 June 2013)

Survival was also discussed in comparison to HNCs without HPV as a cause:

'Treatments such as chemotherapy, radiotherapy and surgery are often more successful in mouth and throat cancers caused by the virus than those caused by tobacco and alcohol'. (*MailOnline*, 16 July 2013)

Diagnosis and treatment: Early diagnosis of HNC was mentioned as giving a 'better chance of successful treatment' by 14/112 (13%) articles.

'Mouth cancer survival rates of about 50% haven't changed in decades, but if the disease is caught early patients can have a 90% chance of a cure'. (*Daily Mirror*, 28 February 2014)

Treatment methods, particularly chemotherapy and radiotherapy were mentioned, as well as the possibility for less invasive treatment in the future.

'Given that subgroups of people with HPV-related H&N [head and neck] cancers display excellent survival, these patients may in future be offered less aggressive treatment'. (*The Western Mail*, 25 February 2013)

Symptoms and screening: Symptoms of HNC were reported more frequently in tabloids and middle-market newspapers than in broadsheets (Table 5.1).

'If you have an ulcer that doesn't heal after three weeks, see your dentist or doctor'. (*Daily Mirror*, 28 March 2008)

The importance of dentists was emphasised, explaining that they play a vital role in HNC diagnosis as well as doctors. Advice was given as a slogan 'If in doubt, get checked out' and ways to look for symptoms of HNC were suggested.

'Men are advised to check their neck for lumps when shaving and both sexes to look at the back of their throat while brushing their teeth'. (*MailOnline*, 13 November 2013)

Case studies were also included and often illustrated the symptoms of HPV-related HNC, the invasive treatment involved, and the importance of regular dental check-ups.

Cited research: Fewer than half (42/112; 38%) referred to research findings from peer-reviewed journals. Research that was cited included studies showing the increase in incidence and burden of HPV-related HNC, showing evidence for oropharyngeal cancer patients carrying antibodies to the E6 protein from the HPV16 virus (Kreimer et al., 2013) and evidence for number of oral sex partners as a risk factor for HPV (D'Souza, Kreimer, et al., 2007).

HPV vaccination for boys

The link between oral sex and HNC was given as a strong case for boys to be vaccinated against HPV. HPV Action, a group campaigning for the vaccination of boys, was mentioned in three articles. Many of the articles covering news of campaigns to vaccinate boys spoke of the opportunity for the vaccine to reduce the number of HNC cases in men, calling for it to be 'a gender neutral vaccination'.

'Campaigners are calling for boys to have the jab too in order to stem the "catastrophic rise" in cancers'. (*Daily Mirror*, 28 February 2014)

Arguments were made about the cost effectiveness of introducing the vaccine for boys (5/112; 4%) and that 'the Government could save thousands of lives and hundreds of millions of pounds for the NHS by vaccinating boys against a cancer-causing virus at a cost of around £20m a year' (*The Independent*, 2 February 2014).

An argument for vaccinating boys against HPV was also made with reference to other countries as Professor John Ashton said 'It makes sense to give teenage boys as well as girls the HPV vaccine, which is already happening in Australia' (*The Guardian*, 19 September 2013).

Men who have sex with men were also acknowledged as an unprotected group in a number of articles (7/112; 6%).

'We [Department of Health] recognise that the current vaccination programme does not offer protection against HPV-related cancers for gay men'. (*The Independent*, 2 February 2014)

It was acknowledged that the HPV vaccination would have to be repositioned, as parents currently know it as 'the cervical cancer vaccine'. There was also recognition that HNC is not the only HPV-related cancer to affect boys and that the virus is linked to anal and penile cancers.

Experts were quoted as being in favour of HPV vaccination for boys, including Professor Maura Gillison, who published evidence of the link between HPV and HNC:

Professor Maura Gillison - 'The time has come to have a more thorough discussion about the potential benefits of HPV vaccines in boys ... When my patients ask whether they should vaccinate their sons [with the HPV vaccine], I say 'certainly'. The vaccine will protect them against genital warts and anal cancer and - as a potential by-product of that - it may protect them against oral cancer caused by HPV ... The time has come to consider offering the HPV vaccine to boys'. (*The Independent*, 21 February 2011)

Professor Margaret Stanley – 'It is not ethical, fair or socially responsible to have a public-health policy that forces men to rely on herd immunity, which won't be reached for decades'. (*MailOnline*, 3 June 2013)

Jamie Rae of The Throat Cancer Foundation and HPV Action, expressed the view that not vaccinating boys is 'inequitable - in fact, I'd say it's an infringement of human rights, for all boys' (*The Independent*, 2 February 2014) and it is 'a flawed and discriminatory policy' (*The Herald* (Glasgow), 12 June 2013), in the campaign to vaccinate boys against HPV.

5.4 Discussion

This study is the first to analyse print and online newspaper coverage of the link between HPV and HNC in the UK. Coverage of the link between HPV and HNC has increased in response to major news stories. Articles reporting the link between HPV and HNC increased in March 2012 as figures showed HNC cases to be rising. Michael Douglas' disclosure in June 2013 sparked an increase in media interest as well as discussions about vaccinating boys. The main themes found to be reported in UK publications were Michael Douglas' disclosure, the riskiness of oral sex, health information including HPV as a cause of HNC and its incidence, and the need to vaccinate boys against HPV.

All the articles tended to report similar content and the themes remained consistent across the types of publication (e.g. broadsheet or tabloid), but how this was presented did differ across publication type. Broadsheets were the first type of publication to report on the link in October 2001, followed by tabloids in February 2004 and middle-market in November 2009. Results from peer-reviewed research were reported in fewer than half of the articles. Basic facts about HPV were not reported in all articles, indicating that the public does not always receive even basic information which could help relieve any anxieties. This was also found in an analysis of the coverage of information about cervical cancer following Jade Goody's illness, with there being very little information included in these articles about HPV (Hilton & Hunt, 2010). Using 'human interest' stories such as the story of Michael Douglas, has been reported previously to be an effective way to engage audiences and can influence what is included or excluded from the coverage (Hilton et al., 2010; Menashe, 1998).

Articles focusing on Michael Douglas' disclosure were more likely to appear in broadsheets than the other types of publication, which is probably due to the interview being conducted with a *Guardian* reporter. Previous research has suggested that events such as a celebrity cancer diagnosis can create news coverage substantial enough to influence health behaviours such as attending cancer screening (Lancucki et al., 2012; Stryker, Moriarty, & Jensen, 2008). Oral sex was said to be the cause of Michael Douglas' cancer in articles talking about his disclosure, but there were not many articles addressing what HPV is and the risk factors associated with it. There was a missed opportunity to educate the public as many articles did not discuss the signs and symptoms of HNC and what individuals should do if they find a symptom. This supports

findings in a previous study analysing cervical cancer coverage where the media failed to provide the signs and symptoms of cervical cancer, or the risk factors (Hilton & Hunt, 2010). Tabloid and middle-market newspapers covered these more often than broadsheet newspapers, but only tabloid newspapers mentioned HPV in their coverage on Mouth Cancer Awareness Month, held in November every year. As different newspapers appeal to different demographics, it is important for communication of HPV and HNC to be consistent across all newspaper types to minimise inequalities in awareness and consequently health outcomes. Previous research has suggested that in general, individuals who are more frequent users of the media are better informed (Chew, Palmer, & Kim, 1995). Attending to health news in newspapers has been shown to be associated with age, income and education, with income and education being found to strongly predict cancer prevention knowledge (Stryker et al., 2008).

Many of the references to oral sex related to the transmission of HPV. Some of the articles placed emphasis on the risk of oral sex, reporting that those with HPV-related HNC are 'more likely to be connoisseurs of cunnilingus and fellatio'. These comments risk HPV-related HNC being seen as a sign of promiscuity and sensationalise it rather than including facts and presenting an HPV infection as common. This, in addition to information based on the evidence presented in chapter 1 about the rising incidence of HPV-related HNC, could lead the public to overestimate the prevalence of HPV-related HNC. Findings from the cervical cancer literature have shown that normalising HPV by emphasising its high prevalence and association with normal sexual behaviour has been effective at minimising negative psychological outcomes such as stigma or embarrassment (McCaffery et al., 2006; Waller et al., 2007). This information is also important for the partners of those diagnosed; I found that some articles suggested Michael Douglas could have contracted HPV from his wife, Catherine Zeta-Jones and could suggest that she was to blame.

As Michael Douglas affirmed that he was talking about causes of HNC more generally, rather than being specific to him, this could also cause stigma towards HPV-related HNC, as the public may feel that he was ashamed to admit his throat cancer was caused by oral sex. There is also the concern that those who have been diagnosed with HPV-related HNC will feel stigmatised (Baxi et al., 2012; Daley et al., 2010; Kahn et al., 2005; McCaffery et al., 2006; Milbury et al., 2013), so it is important that appropriate messages are being given about HPV to reduce the

stigma associated with this sexually transmitted infection (Braun & Gavey, 1998). Including case studies may help the public empathise with the person in the case study and reduce stigma. However, case studies reported in the articles were used to illustrate some of the symptoms for HPV-related HNC and how invasive and challenging the treatment can be. Endorsements from case studies where symptoms were noticed, and highlighting good prognosis with early diagnosis may encourage the public to adopt health protective behaviours such as checking for lumps and attending the dentist regularly.

Articles which included reasons for vaccinating boys used case studies, Michael Douglas and research to support their campaigns. The media has been shown to increase knowledge of HPV after coverage of the introduction of the HPV vaccination (Kelly et al., 2009; Patel et al., 2016). Media coverage of the campaigns and the connection to Michael Douglas' disclosure has the opportunity to raise awareness among parents and as all the articles took a positive stance towards vaccinating boys, this may influence parents' decisions about vaccinating their sons against HPV. Including endorsements from leading researchers in the field of HPV and HNC may have enhanced the credibility of messages in the articles and encouraged parents to vaccinate their boys should they have the opportunity. Parents of boys will need to be able to communicate to their sons the link between HPV and sex, given that the vaccine is currently positioned as the 'cervical cancer vaccine'. The media could play a role in facilitating this.

5.5 Strengths and limitations

This study showed both the trends in coverage of the link between HPV and HNC in UK publications and also gives further detail on the content of these publications. The use of the NexusUK database ensured the search was up-to-date at the time it was conducted. Using NexusUK database to search for media coverage has been shown to be as effective as conducting the search by hand (Wells, Marshall, Crawley, & Dickersin, 2001). As with any qualitative research, the analysis and interpretation was subjective. The interpretation could be influenced by my pre-existing perceptions, but by including others in the analysis process it is hoped that this will have minimised any personal biases and idiosyncrasies. Also by presenting quotes in the results section, this enables others to assess my interpretation of the data and provides data transparency (Moravcsik, 2014). The overall reliability of the coding of the content of the publications represented substantial agreement between myself and Dr Alice Forster, and

these methods for validating the interpretation of the data followed those used in previous research.

This study is limited to UK publications and to print and online media, with broadcasts on television not examined, and so the results may not be representative of wider information available to the public. Different content may have been presented in television broadcasts which have not been picked up in this study. It is also important to recognise that although the media is a common source of information, it is not the only source. The internet is becoming increasingly popular as a source of health information, with over 154 million websites containing health information (Young, 2011). This figure is likely to have now increased since the publication of these statistics five years ago. The increasing use of social media could play a significant role in the dissemination of health information and an interesting area of research to explore would be the content of blogs and social networking sites, such as Facebook. Through Facebook, it is also possible to search for health information and to join patient groups (Young, 2011).

The articles in the study were only examined for content and not for accuracy of the information presented as this was not an aim of the study. Therefore it is not possible to determine if the health information covered in these publications was completely accurate, but this would be an interesting area to examine in future research. Assessing public knowledge about the link between HPV and HNC would also be useful, and an important first step towards raising public awareness and designing appropriate information for patients diagnosed with the disease.

5.6 Conclusion

This study is the first to show that the link between HPV and HNC has received coverage in the UK media, but an opportunity was missed to educate the public and influence health behaviours, through the disclosure of Michael Douglas. It is important for researchers not only to monitor media coverage of the link, but to work with journalists to ensure the content of articles is accurate and appropriate. Transmission of HPV via oral sex was regularly discussed, along with the link between HPV and HNC, which could raise public anxieties about oral sex. It is therefore important for journalists to aim to minimise stigma and blame associated with these messages, normalising HPV and portraying it as associated with normal sexual behaviour.

Examining responses to articles presenting the link between HPV and HNC through analysis of the discourse of online comments made on these articles would be an interesting area for future research. Patients diagnosed with HPV-OSCC may have read about the relationship between HPV and HNC in the media and there may be differing levels of knowledge when they are diagnosed. As health professionals are a trusted source of information and are likely to be a key source of information for patients, chapter 6 interviews health professionals directly caring for HNC patients, some of whom are now being diagnosed with HPV, to assess the information given to patients when they are given a diagnosis of HPV-OSCC.

CHAPTER 6. AN EXPLORATORY INTERVIEW STUDY WITH HEALTH PROFESSIONALS (STUDY 3)

6.1 Introduction⁶

The systematic review in chapter 4 showed that knowledge of HPV and head and neck cancer (HNC) was generally low in general population samples, and the previous chapter has shown that UK media covering the link between HPV and HNC did not always provide detailed information about HPV and often lacked basic facts the public may want to know. As these basic facts are often missing, it is possible that if diagnosed with HPV-OSCC, patients are also not aware of the relationship between HPV and OSCC and this may create unnecessary anxieties. Based on these results, it was deemed important to explore what health professionals tell their patients about HPV and HNC and what information they think is important to give them. The term OSCC will be used in this chapter as the majority of the HPV-positive patients that health professionals will have discussed HPV with will have been diagnosed with OSCC, although I recognise that health professionals will have also treated patients with other HNCs.

Sharing the diagnosis of HPV-OSCC imparts not only a cancer diagnosis, with all the associated psychological implications that were discussed in chapter 2, but also conveys the information that the cancer was caused by a sexually transmitted infection. In the USA, HPV testing has been introduced as a clinical standard of care in oropharyngeal cancer in the National Comprehensive Cancer Network guidelines (Pfister et al., 2012). HPV tumour detection is also taking place in some UK centres (Roe et al., 2014), and guidelines have been published recently in the UK by NICE (National Institute for Care and Excellence, 2016; see section 1.6). Now HPV testing of tumours is more commonly carried out, the HPV status of the tumour is available to be communicated to patients.

The sexually transmitted nature of HPV creates a potential challenge for health professionals with little experience of discussing sexual behaviour (Daley et al., 2011; Kahn et al., 2007; Riedesel et al., 2005). Evidence from the cervical cancer literature suggests that general practitioners and practice nurses often lack knowledge of HPV and find the topic sensitive,

⁶ A version of this chapter has been published in *Head and Neck* (Appendix 6.1)

awkward, and difficult to explain in a way patients can understand (McSherry et al., 2012).

Some also questioned the need to mention HPV at all (McSherry et al., 2012). As described in chapter 3, an HPV diagnosis in the cervical cancer screening context has the potential to cause feelings of stigma and shame in addition to the anxiety and health concerns usually associated with abnormal cervical screening results (McCaffery et al., 2006). In the absence of any formal recommendations for discussing HPV test results with OSCC patients, a recent review (Fakhry & D'Souza, 2013) suggested that the cervical cancer literature could be used as a starting point.

A small amount of research with HPV-OSCC patients has begun in the USA and results from these studies could be used in conjunction with the cervical cancer literature in providing a starting point for health professionals when discussing HPV test results with OSCC patients. A qualitative study with male HPV-OSCC survivors (n=10) in New York found physicians were the primary source of information for all participants who wanted to know about HPV (Baxi et al., 2012). In a larger study (n=62) exploring the information needs of HPV-OSCC patients in Texas (Milbury et al., 2013), around half reported that their oncologist did not discuss issues related to HPV with them. Many of these patients sought information about HPV and their cancer elsewhere.

It has been argued that health professionals have an ethical obligation to ensure accuracy and transparency when disclosing HPV as the cause of a patient's cancer (Shuman & Wolf, 2010), but as yet there have been no studies exploring the discussion of HPV-OSCC among health professionals themselves. Therefore, I carried out an exploratory qualitative interview study with health professionals treating patients with HPV-OSCC (as well as other HPV-HNCs), exploring their experiences and the perceived challenges of talking to patients about HPV in this context. This work aimed to help identify needs for information materials which may encourage the discussion between health professionals and their patients.

Qualitative research is valuable in behavioural science as it allows full exploration of the experiences, attitudes and beliefs of participants and the data are not constrained by closed questions. Qualitative research involves the use of open-ended questions and participants are probed in response to their answers (Guest, Namey, & Mitchell, 2013). It allows rich and detailed data to be collected in often very new areas of research that require exploration and description (Pope & Mays, 1995; Yardley, 2000). In behavioural science, qualitative research is

often used in this way, to explore new areas of research which can then later be used to help inform future research and data collection through quantitative measures.

This study aimed to answer the fifth research question of my thesis:

- 5) What are the experiences and views of health professionals in the UK who care for patients with HPV-OSCC?

6.2 Methods

6.2.1 Ethics

This study was approved by the UCL Research Ethics Committee, reference 4577/002 (Appendix 6.2).

6.2.2 Recruitment

I recruited health professionals from different disciplines caring for patients with HPV-OSCC, using purposive sampling to explore a range of perspectives. Participants were recruited from eight research-active hospitals in England and Wales (see Table 6.1), where HPV is discussed with patients. Potential participants were initially identified through existing contacts of Dr Jo Waller (two surgeons and two oncologists) and contacted via email. Snowballing is a method to identify new participants. It involves asking participants who are already taking part in a study, to contact others who they think might also be willing to take part. This method was subsequently used to recruit further health professionals as at the time, I did not have many contacts with health professionals working with OSCC patients. I also attended multidisciplinary team meetings at two hospitals in London to introduce the study and recruit participants.

My relationship with the participants prior to the interviews involved contacting them to arrange, and later confirm the interviews. The participants were aware that I was a researcher interested in their experiences of discussing HPV with their patients, which was explained on the study information sheet (Appendix 6.3) provided to them prior to them consenting to take part.

Initially I aimed to purposively recruit 10 participants to include oncologists, surgeons and nurses, as they have the most contact with HPV-OSCC patients. There are no set guidelines for sample size in qualitative research, but one such recommendation is to include between six and

eight interviews for homogeneous samples and 12 to 20 when looking to find maximum variation (Kuzel, 1992). As this was an exploratory study interviewing different subgroups of health professionals and I was unsure whether the results were likely to be homogeneous, I decided to aim for 10 interviews as a starting point. The emerging themes were noted for each interview. As the study progressed additional professional groups were included as other health professionals expressed that they were also key to HPV-OSCC patients' care, and to try to maximise the range of views.

Prior to the interview, each participant was provided with a study information sheet and completed a short demographic questionnaire which included questions about their age, sex, ethnicity, highest level of qualifications, profession, how many years they had been practicing in their profession, where they work, an approximation of how many HPV-positive HNC cases are seen in their centre each year and how many of these they are involved in (Appendix 6.4), and provided written consent (Appendix 6.5). Participants were also given a short debrief at the end of the interview (Appendix 6.6). Emerging themes from the interview transcripts were noted simultaneously with carrying out the interviews. Once I was satisfied that no new themes had emerged from three consecutive interviews, this suggested that saturation had been achieved. Data collection ceased at this point (Francis et al., 2010).

6.2.3 Procedure

I carried out semi-structured interviews with the health professionals following a topic guide that I developed using the existing literature on patient experiences and previous work on HPV and cervical cancer. It covered the participants' professional background and experience of working with HNC patients, and their experiences of and attitudes towards communicating with patients about HPV-OSCC (Appendix 6.7). Suggestions for facilitating communication in the future were also discussed.

Interviews took place face-to-face at the participant's workplace (n=7) or over the telephone (n=8), lasted 20-40 minutes and were digitally recorded. I conducted all the interviews and transcribed them verbatim. Transcripts were not returned to the participants for comment or correction as this is time-consuming, participants' perspectives may have already changed due to experiences since the interview, and it is possible they might want to change their responses to be more socially desirable.

6.2.4 Analysis

The interviews were analysed using Framework Analysis (Ritchie & Spencer, 1994), which is a popular method of analysing qualitative data in health research (Gale, Heath, Cameron, Rashid, & Redwood, 2013). This approach involves the five stages of familiarisation, identifying a thematic framework, indexing, charting and mapping, and interpretation. The data are organised into a thematic framework which enables close inspection of the data by theme and by participant. The matrix produced in Framework Analysis also enables the data to be easily analysed by either the participant or theme. This approach was considered more suitable than other qualitative analytical methods because the data was not aligned with a particular theoretical approach. Other qualitative approaches include Grounded Theory which focuses on generating theory; Interpretive Phenomenological Analysis (IPA) which focuses on the individual experience; Discourse Analysis which focuses on interpreting language and how it has been constructed; and Ethnography which focuses on the individual in the wider social and cultural context.

I became familiar with the interviews by listening to, transcribing and reading the transcripts. I made notes on recurring themes and each interview was summarised. Each transcript was coded, after which themes were identified and developed into a thematic framework with subthemes under each main theme. Using the qualitative package NVivo 10 (QSR, 2012), the data were summarised and charted into a matrix, where each column represented a subtheme and each row represented a participant. Initial codes were developed with input from Dr Jo Waller and Dr Laura Marlow and then later checked for agreement against the final coding framework. There were few disagreements in interpretation and those that did occur were resolved by discussion.

6.3 Results

Thirty health professionals were approached and I interviewed 15 from a range of professional groups in June 2013, yielding a response rate of 50%. Three of the 15 health professionals who were not interviewed were willing to take part if they were needed and consisted of one male surgeon, one female surgeon and one male oncologist. The other 12 non-responders consisted of three males and nine females. These were a mix of clinical nurse specialists and surgeons.

There was an equal mix of male and female health professionals working in hospitals, with most being from White British backgrounds. Characteristics of the sample are shown in Table 6.1.

Table 6.1: Sample characteristics

Sample characteristics (n=15)	
Age [median (range)]	47 (33-59)
Sex [n]	
Male	8
Female	7
Ethnicity [n]	
White British	13
Other	2
Profession [n]	
Surgeon	5
Clinical oncologist	3
Specialist nurse	4
Research nurse	1
Specialist radiographer	1
Speech and language therapist	1
Geographic place of work [n]	
North West England	4
North East England	2
South West England	1
London	4
South East England	3
Wales	1

Representing the views and experiences of these health professionals, seven main themes emerged: The significance of HPV in OSCC, attitudes to discussing HPV, challenges to discussing HPV, dealing with the impact of HPV on relationships, patients concerns and questions about HPV, key messages and professional development (Table 6.2).

Table 6.2: Framework of themes and subthemes

Theme	Subtheme
Background	1 Background with head and neck cancer patients
	2 Research
	3 HPV testing
	4 Vaccination
	5 Perceptions of colleagues
The significance of HPV	1 Patient characteristics
	2 Important topic
	3 Epidemiology
	4 Survivorship and treatment
	5 Impact on the future
Attitudes to discussing HPV	1 Reasons for discussing HPV
	2 Reasons against discussing HPV
Challenges to discussing HPV	1 Lack of knowledge
	2 Talking about sexual health
Dealing with the impact of HPV on relationships	
Patient concerns and questions about HPV	
Key messages	1 Normalising HPV <ul style="list-style-type: none"> a. High prevalence b. Normal sexual behaviour c. Link with cervical cancer/HPV vaccination
	2 No need to change behaviour
	3 Positive prognosis
Professional development	1 Learning from experience
	2 Learning from others
	3 Training

6.3.1 The significance of HPV in OSCC

All participants regarded the role of HPV in OSCC as an important issue, describing HPV-OSCC as a 'different disease entirely' (P9, female, specialist radiographer), affecting younger, otherwise healthy patients. The rise in incidence was a key concern. Participants reported being able to tell which patients had HPV due to their appearance and demographic background, which differed from the patients they usually treated. As one oncologist reported:

'When I first started in head and neck cancer practice, the stereotype of the head and neck cancer patient was pretty well fulfilled in that most of our patients were alcohol dependent, nicotine dependent and had developed head and neck cancer as a consequence of those two risk factors, but we have seen a change ... over the last ... decade where increasingly we're seeing younger, non-smoking, non-drinking patients who are on average 10 years younger and recognising in that patient group that their HPV associated disease is the main risk factor for that'. (P3, male, clinical oncologist)

The clinical implications of HPV-positive OSCC were discussed by a number of participants, including patients living longer with the after-effects of treatment and patient demands for expedited rehabilitation. One participant explained the impact of this:

'We've got a longer period of survivorship for younger people who are still actively employed and so their functional rehabilitation becomes a bigger issue so that's going to be a bigger part of our case load'. (P12, female, speech and language therapist)

6.3.2 Attitudes to discussing HPV

Almost all participants had talked about HPV with their patients, but even those who did not have direct experience of discussing HPV were able to express their opinions on the issue. Views about disclosing HPV as the cause of a patient's cancer varied, perhaps reflecting the lack of guidelines for discussing HPV. There was a range of views on the possible benefits of discussing HPV status with patients.

Participants who felt it important to discuss HPV status believed it was 'helpful for the patient's psyche' (P4, male, surgeon) to understand the cause of their cancer. Sometimes patients had done their own research about HPV and had become 'scared about it' (P10, female, clinical oncologist), making it important to provide them with accurate and reassuring information. A clinical oncologist described how patients would search for information about HPV on the internet, and felt that avoiding the issue in the clinic was unhelpful.

In centres running clinical trials, it was viewed as difficult not to mention HPV, because HPV status determined eligibility which 'forces the issue' (P2, male, surgeon). One reason for discussing HPV was the positive prognosis of HPV-OSCC, which participants felt had a direct impact on the patient and was seen as 'one of the major bits of information they want to know' (P6, male, surgeon).

Participants who did not discuss HPV status with patients felt it unnecessary to mention HPV because it is 'not offering a modifiable risk factor' (P3, male, clinical oncologist) and focusing on the cause may contribute to self-blame for past behaviour:

'When it comes to HPV disease, I mean what can you tell them? ... There's nothing that they need to adapt in their lifestyle which is going to make any difference to their outcome at all'. (P7, male, surgeon)

One view was that patients were not concerned about the cause of their cancer during the diagnosis consultation, where other worries and discussions about treatment took priority: 'not a single patient that I've met so far has asked me what's caused their cancer' (P7, male, surgeon). It was sometimes felt to be best to 'leave it at that stage, to the patient and their family

[to raise]' (P1, male, surgeon) due to the fact that it does not change the clinical management. The consultation was sometimes described as being patient-directed and if patients did not ask about it, HPV 'may just not come up' (P3, male, clinical oncologist). Some participants said they were increasingly raising the issue of HPV with their patients, whereas others described patient-led consultations. Mentioning clinical trials prompted patients to ask questions, but one surgeon reported 'less than 10% of patients coming back at a later stage to discuss the implications [of HPV] in a social context' (P1, male, surgeon).

Variations in attitudes towards communicating about HPV among health professionals were described, including a difference between surgeons and clinical oncologists:

'I would say the oncologists talk about it much more easily and freely and openly, whereas the surgeons might mention it, but they don't go into how it's caused, the whole thing about HPV. No, I'd say oncologists are better at communicating about it'. (P8, female, specialist nurse)

6.3.3 Challenges to discussing HPV

Health professionals described two main concerns when talking to patients about HPV: the limitations of their own knowledge about the virus and discomfort talking about sexual health matters.

Lack of knowledge

It was apparent that some of the health professionals felt they lacked knowledge to respond to some of the questions patients asked about HPV, with a specialist nurse reporting 'no bottom to those questions' (P11, female, specialist nurse). It appeared there was some uncertainty about where to find accurate information, with consultants sometimes reported as giving different information to that printed in journals: 'he [consultant] said 'Oh it's not an epidemic' ... am I supposed to go with what he says, or am I supposed to go with what's in the journals?' (P11, female, specialist nurse). The issue was raised of not feeling well informed, while it was suggested that some questions are difficult to answer due to the limits of scientific knowledge:

'They [the patients] start asking questions about how I caught HPV and when I caught it and who I caught it from, how will I have caught it. And some of those questions are difficult to answer because we don't have the scientific knowledge at the moment ... it's still quite confusing I think both for the doctors and for the patients'. (P5, male, clinical oncologist)

Being honest with patients about not knowing the answers was advocated, since there is still scientific uncertainty:

'One of the questions I have been asked is 'So now the cancer's gone, if I have oral sex again, is it going to come back?' I don't know that answer, I don't know if anybody does know that answer ... if the questions are difficult like that, I tend to say there's a lot of research on the go at the moment and we don't have all the answers to the questions'. (P13, female, research nurse)

There was some evidence of discomfort talking about HPV with patients. A specialist nurse said: 'I'd feel out of my depth pretty quickly if people had been on the internet and they'd heard this and heard that' (P11, female, specialist nurse). However, confidence appeared to increase with experience of discussing HPV with patients, with an oncologist describing how she felt she could now honestly say 'nobody knows the answer' (P10, female, clinical oncologist).

Talking about sexual health

Health professionals working with head and neck cancer patients are not used to discussing sexual health and some participants were very aware of this:

'You end up getting into the field of how was the virus transmitted and you say well it'll be broadly speaking through sexual contact and actually it's uncommon for patients to want that spelt out, but just occasionally I've got into a conversation between like as it were vaginal sex, oral sex, kissing and all of that. People want it spelt out in words of one syllable, but I think to be honest most head and neck consultants get pretty squeamish about that'. (P2, male, surgeon)

Observations were raised about participants' colleagues:

'I'm very lucky to work with some extremely talented surgeons, ... but I think talking about HPV takes them out of their comfort zones somewhat ... they are empathetic enough communicators to know what they're not good at and I think they'd know that they're straying out of their comfort zone; better not to get into it'. (P3, male, clinical oncologist)

In addition, the issue of potential blame or 'finger pointing' (P6, male, surgeon) in relation to sexual transmission was raised. One participant observed that 'it can be particularly difficult when you have couples in a session' (P12, female, speech and language therapist). There were also concerns about not wanting to give the information in the 'wrong manner' and worry about patients leaving the consultation blaming themselves.

Not all participants reported difficulties talking about sexual matters, with the speech and language therapist being experienced in, for example, dealing with 'difficult questions about ...

engaging in sexual practice when I have a stoma' (P12, female, speech and language therapist).

6.3.4 Dealing with the impact of HPV on relationships

It was suggested that consultations could be influenced by the presence of the patients' partners and that some patients were more open to discussion about HPV without their partners present. For example, one couple had researched HPV prior to the consultation and the partner was concerned about whether HPV indicated infidelity:

'Both husband and wife had done their homework, they knew about HPV, they knew he was likely to be HPV-positive before the consultation started ... but the main crux of this issue was that ... the wife was [saying] 'How's he got it, when did he get it'. As far as the wife was concerned they'd been in a monogamous relationship for 15 years and she felt ... this must be a sign that he'd been unfaithful and had other partners outside of the marriage ... that was obviously causing some problems between the two of them'. (P5, male, clinical oncologist)

The techniques described for normalising HPV, through emphasising its high prevalence, explaining it is a result of normal sexual behaviour, linking it to cervical cancer and the HPV vaccination, explaining to the patient there is no need to change their behaviour and giving a positive prognosis, were used to try and diffuse the issues around past and/or present sexual activity (see section 6.3.6). Surgeons and oncologists often tried to help patients realise it was not their fault and that there was nothing they could have done to prevent their cancer.

Fear of transmission and self-blame among partners were also described. In one case, a couple had ceased sexual activity following a consultation, which had led the clinical oncologist to re-assess how issues of sexual transmission should be communicated:

'We've been on a real learning curve with that [discussing HPV] and I know I got it wrong initially ... we talked about it with a patient and in subsequent discussions with the support workers, that patient was not having sex with his wife anymore because he was worried he would infect her with HPV'. (P3, male, clinical oncologist)

A surgeon also recognised the nature of the relationship as important when deciding how much to discuss in the consultation:

'I was just slightly cautious ... about discussing with partners the number of partners someone else has had ... because obviously it was a newer relationship, not a sort of you know 20 years married type one'. (P6, male, surgeon)

6.3.5 Patient concerns and questions about HPV

Almost all participants gave examples of concerns and questions patients had expressed about HPV. Views differed amongst health professionals about what patients' primary concerns were. Some participants reported concerns mainly about diagnosis and treatment; with others reporting concerns and questions about HPV and transmission (see previous section). One specialist nurse reported an experience with a patient worried about transmitting HPV to his wife and re-infecting himself if he continued to practice oral sex. This patient was also worried about his son and talked about getting him vaccinated:

'I had this one guy who was HPV-positive and obviously he was really worried about passing this onto his wife or being re-infected by HPV if he continued to practice oral sex... He also was really worried about his son ... because he knew that girls are being vaccinated against the HPV virus. He was worried that his genetic makeup, that he's developed a cancer by the HPV virus, that his son was going to and he was looking into getting his son vaccinated privately'. (P15, female, specialist nurse)

Specialist nurses described how some patients 'come armed with' (P8, female, specialist nurse) lots of questions about implications for transmission and the chances of becoming re-infected, but also noted that others 'probably wouldn't ask many questions' (P11, female, specialist nurse). Some nurses thought that patients felt more comfortable asking them questions than the surgeon or clinical oncologist. This was acknowledged by some surgeons who said that it was the specialist nurses who were asked follow-up questions. Nurses and allied health professionals tended to see it as their role to be 'the patients' advocate' (P8, female, specialist nurse), checking whether they had any questions following the consultation.

6.3.6 Key messages

Several key messages about HPV were highlighted by participants, suggesting an agreement about core messages perceived to be useful to the patient. These focused on trying to minimise possible negative psychological responses to HPV and presenting the diagnosis in a way that was easy to understand, and emphasised its positive implications. Recognising the amount of information each patient could understand and tailoring communication to avoid overloading them was mentioned by participants as important. It was suggested that delivering information about HPV in a factual manner 'can distance any emotive element' (P12, female, speech and language therapist), with the aim of 'not making a big deal of it' (P10, female, clinical oncologist).

Normalising HPV

Participants reported a range of ways they would try to normalise HPV infection and reduce its psychological impact. This included describing the high prevalence of HPV, highlighting that transmission is through normal sexual behaviour and using the context of cervical cancer and HPV vaccination.

High Prevalence

HPV was often normalised by explaining that anyone who is sexually active will have been exposed to it: 'it's just really a difference between how the body deals with it in different people' (P4, male, surgeon). The importance of communicating the fact that HPV is 'a ubiquitous problem' (P5, male, clinical oncologist) was emphasised; a surgeon reported telling his patients that HPV is as common as flu, calling it 'genital flu' (P6, male, surgeon).

Normal sexual behaviour

Participants emphasised that HPV was caused by normal sexual behaviour and was not an indication that the patient was promiscuous: 'this is something which is associated with probably any sexual relationship ... it's not like getting a dose of gonorrhoea or chlamydia' (P4, male, surgeon). It was suggested that by being deliberately vague about the nature of transmission, it was possible to reassure the patient that almost anything could have caused it: 'I say you can get it from kissing somebody ... that may not be the most common way to get it but you could do' (P5, male, clinical oncologist). Participants also emphasised the fact that HPV is an infection likely to have occurred a long time ago and that the patient had 'not gone out and slept with an infected individual' (P4, male, surgeon).

Link with cervical cancer/HPV vaccination

Referring to HPV in the context of cervical cancer was reported to help patients understand that the same virus is involved in both cancers. Mentioning the HPV vaccination programme was thought to convey to the patient that this virus 'isn't something special' (P3, male, clinical oncologist) and one surgeon described how he would explain this:

'I always explain that it's the same virus that's related to cervical cancer and that anyone that's sexual active will have been exposed to it, hence the vaccination programme for pre-sexually active individuals'. (P4, male, surgeon)

No need to change behaviour

When patients were concerned that they had 'caused' their cancer, participants reassured them that there was no need to modify their behaviour. Participants explained how they would tell patients with cancer related to tobacco and alcohol use to change their behaviour as this was important for their prognosis, whereas for HPV-OSCC patients 'there's no change in their behaviour related to the sexual practice right now that you're advising them to take' (P2, male, surgeon), as this would not affect the outcome.

Positive Prognosis

Participants tried to convey the positive prognosis of HPV-OSCC, with one clinical oncologist reporting how this information is useful:

'I think where knowledge of HPV status is useful to the patient, is enabling them to understand yes, you've got head and neck cancer, but we know that this particular head and neck cancer carries a much better prognosis than other forms of head and neck cancer'. (P3, male, clinical oncologist)

Conveying the message about prognosis was viewed by most of the health professionals to help counter any feelings of blame and guilt among patients seeing this as 'a bit of good news for them' (P7, male, surgeon) and was sometimes accompanied by a comparison to HNC related to smoking and other risk factors, using terms such as doing 'better in the long-term' (P4, male, surgeon) and a 'better prognosis' (P6, male, surgeon).

It was recognised that the positive prognosis of HPV-OSCC could lead to less intensive treatment in the future which is less toxic and leads to less dysfunction in these patients:

'More people are realising this is a separate disease and that we may be over treating them with that and as 80% of these patients tend to survive, we need to be looking at long term survivorship and functional outcomes that they survive with'. (P7, male, surgeon)

6.3.7 Professional development

Learning from experience

As health professionals saw an increasing number of HPV-OSCC cases, they felt they had begun to learn what is relevant for patients. One clinical oncologist described how in the past he had 'mentioned unnecessarily orogenital transmission and that's not actually relevant' (P3, male, clinical oncologist).

A transition was evident, from participants previously talking about contracting HPV through oral sexual behaviours, to now talking about most sexually active people contracting HPV. In some cases, participants reported having identified areas of discussion they avoided because of their lack of knowledge. They had since made an effort to find out more, resulting in increased confidence and more open discussions about HPV. Knowing the latest research and reading the literature was of upmost importance:

'I mean for us it was finding out more information and having the knowledge to answer questions ... then also just learning from experience about the types of things that people are asking, ... doing your best to find out what the answer to that question is for the next person to ask. Because if one's [patient] going to ask, the next are'. (P15, female, specialist nurse)

Learning from others

Regular team updates and feedback with colleagues were mentioned as useful to improve dissemination of information to the patient in the future. It was acknowledged that colleagues 'think differently' (P1, male, surgeon) so working as a multidisciplinary team was viewed as very important.

Attending conferences was also perceived as a valuable way to both increase knowledge about the area and learn alternative ways to discuss HPV-OSCC.

There was agreement over the need to add to and provide consistent information to patients with HPV-OSCC:

'Incorporating it in our ... patient information ... I certainly think that there will be serious room for improvement in that'. (P14, male, specialist nurse)

It was also suggested that a leaflet and/or guidelines offering advice for health professionals would be useful. Another suggestion was learning from colleagues working in cervical cancer, as they have 'done a very good job in that women with cervix cancer don't get immediately vilified for being sexually promiscuous and that's not the public conception of cervix cancer' (P5, male, clinical oncologist).

Training

Communication workshops and training were mentioned as a way of developing further skills: 'we would be best off receiving some degree of training in terms of how to communicate this information to patients' (P7, male, surgeon). In some centres, communication workshops had already been carried out and participants from these centres felt they had benefited.

6.4 Discussion

This study explored the views and experiences of health professionals talking to patients about HPV in the context of OSCC. Views about discussing patients' HPV status were mixed. Some felt it was beneficial for the patient to know the cause of their cancer, others felt that as clinical management is not currently determined by HPV status, discussing HPV in consultations was not necessary. Most health professionals in this sample did talk to their patients about HPV, with discussions sometimes initiated by the health professional and sometimes by the patient.

HPV was recognised as being significant to the HNC field and was something health professionals described as a 'different disease entirely', and it has been described as this elsewhere and in chapter 1 (Chua, 2014; Scudellari, 2013). It is important to recognise the implications HPV has for health professionals, in particular the changing demographic of patients as they are now younger and are having to live with the after-effects of their treatment for longer. Health professionals also recognised the pressures on themselves for the requirement of expedited rehabilitation in these younger patients, as they are keen to return to their lives as soon as possible (Chua, 2014).

Participants agreed on several key messages about HPV that they felt were important to incorporate into their discussions with patients. Describing the high prevalence of HPV and its link with normal sexual behaviour, and explaining HPV using the context of cervical cancer and HPV vaccination helped to normalise the infection. There is increasing recognition of the need

for appropriate messages and guidance to be developed to aid health professionals in their discussions. The HPV Core Messages study developed messages about HPV vaccination and HPV testing in the context of cervical cancer and recognises the need for appropriate messages to be adapted for patients with other HPV-related cancers (Hendry et al., 2016). The messages developed have not been published and therefore I am unable to compare them to the key messages found in this study. Their current work aims to develop scripted consultations that are 'offering messages that are succinct, salient, reassuring and relevant' (Hendry et al., 2016, p5).

The findings in this study found that discussion of oral sex specifically was deemed unhelpful as it can add stress to relationships as well as create awkward situations where the patient may feel stigmatised. However, recent UK evidence confirms that oral sex is commonplace, with the majority of people reporting oral sexual contact in the last year, and numbers rising in younger age-groups (Mercer et al., 2013). In the cervical cancer literature, the high prevalence of HPV has been an important message to convey to patients and has been shown to reduce stigma and embarrassment (McCaffery et al., 2006; Waller et al., 2007), although the psychosocial implications for HPV-OSCC patients may be different. These participants also felt it was important to explain that HPV-OSCC tends to have a positive prognosis. Qualitative work with HPV-OSCC patients suggests that they are encouraged by this information as patients expressed relief that this was good news for their recovery (Baxi et al., 2012), supporting this as a key message for health professionals to convey. A potential implication of explaining the good survival rates to HPV-OSCC patients is a resulting preference for de-escalation of treatment, as one surgeon described. As mentioned in chapter 1, on-going clinical trials (Mehanna et al., 2012) are exploring the possibility of de-escalating treatment for HPV-OSCCs, so that patients are presented with less intensive treatment options with the hope that the after-effects of treatment may be lessened. Once the results of these trials are published, clinical guidelines should be available. Until then, health professionals may still need to be prepared for conversations about de-escalating treatment, especially with highly informed patients.

Qualitative work with HPV-OSCC patients suggests that questions about HPV are overshadowed by concerns about cancer (Baxi et al., 2012), also described by some of the participants in this study. Some of the nurses I interviewed described a lack of confidence answering questions about HPV largely due to their own lack of knowledge. Given that nurses are often the first point of contact for patients with questions, it is important that information and

training is available to increase their knowledge and improve their confidence for these discussions. Surgeons and clinical oncologists also felt there was a general lack of knowledge about HPV and OSCC, but understood this was due to limited scientific knowledge and were generally confident explaining this to patients. As found in chapter 5, knowledge of the association between HPV and OSCC was higher in health professionals than the general population. It was evident that confidence in discussing HPV with patients increased with their experience of doing so.

Most of the health professionals interviewed felt that additional training could help them improve their knowledge about HPV and communication with their HPV-OSCC patients, supporting previous research with dentists and dental hygienists who expressed a desire for more knowledge and training to improve their communication, as well as improving their comfort levels in discussing sexual behaviour with patients (Daley et al., 2011). Participants in this study acknowledged that these discussions were outside some of their colleagues' comfort zones. This training could take place through communication workshops with a diversity of health professionals. These findings could also contribute to the development of information for health professionals that could be used with patients to communicate about this sensitive topic. This information could include responses to some of the questions posed by patients that have been mentioned by health professionals in this study and help improve the knowledge of health professionals when discussing this with their patients.

Some of the participants interviewed felt that communicating with HPV-OSCC patients was very different from communicating with patients whose cancer was related to tobacco and alcohol use. It was advocated that it was important when communicating with HPV-OSCC patients, to correct the perception that they have done something to cause their cancer, whereas this would not be the case in cancers caused by tobacco and alcohol use. HPV-OSCC patients would usually be given more information about the cause of their cancer, due to the cause being less obvious than with tobacco and alcohol. Communicating about the cause of HPV-OSCC often brought with it the need to discuss sexual behaviour. These discussions have the potential to cause problems in relationships, demonstrated by some of the cases described in this study and previous findings from Baxi and colleagues (Baxi et al., 2012). This should therefore be something health professionals consider when planning treatment and recommending support for patients.

The themes presented can be interpreted within the 'cognitive representation' component of Leventhal's Common Sense Model (CSM) (Leventhal et al., 1980). The identity of the cancer as HPV-related was important for health professionals, distinguishing these patients from those with alcohol/tobacco-related disease. Understanding that HPV was the cause of the cancer led some patients to question how they had acquired the virus, raising issues of sexual transmission and fidelity which some health professionals found challenging to address. Timeline, curability and controllability were salient because prognosis is better in HPV-related cancers, leading to the potential de-escalation of treatment. Consequences included longer survivorship, which was an issue raised by health professionals, and impact on sexual relationships, which was recognised as important for some patients. Consequences were influenced by the demographic of this patient group, who are generally younger. The CSM may provide a useful structure for discussing HPV with OSCC patients, and could be used to inform the development of clinical guidance for HCPs and information for patients about HPV-related OSCC.

The findings from this study mirror those of similar studies in the cervical cancer literature, finding health professionals recognise HPV as a sensitive topic and are reluctant to discuss it, that some patients do not want to know anything about HPV and that there are gaps in health professionals' knowledge (McSherry et al., 2012). This suggests significant overlap in the concerns of health professionals from the two fields. Research into common questions asked by patients (Gilbert, Alexander, Grosshans, & Jolley, 2003; Marlow, Wardle, Grant, & Waller, 2009) and educational needs of health professionals from the cervical cancer literature (Szarewski, 2009) could therefore be useful to HNC health professionals. It is important to consider, however, that the needs and concerns of HPV-OSCC patients are likely to differ from those of women being screened for cervical cancer due, in part, to that fact that a high proportion of HPV-OSCC patients are men (Blomberg et al., 2011; Mehanna et al., 2012) and that in the cervical cancer screening context they are not being treated for cancer.

6.5 Strengths and Limitations

A range of health professionals across England and Wales were sampled to gain perspectives on communicating about HPV-OSCC from different disciplines. This work offers a useful starting point for the development of information for health professionals and potentially to inform larger

quantitative work with HPV-OSCC patients, with the ultimate goal of developing information for patients. Qualitative research is a good starting point for fields of research where there has been currently little research conducted. The findings from this study provide key information about what patients are currently being told and what health professionals are finding difficult to communicate with patients, providing a basis for which further information for these health professionals and their patients can be developed.

Conducting this study using qualitative methods enabled the complexities of the consultation to be discussed which would not be possible in quantitative studies; however I acknowledge a number of limitations to the study. The subjectivity of qualitative analysis has long been recognised, but by involving other researchers in the analysis process this should provide greater reliability of the interpretation of the data. The transparency of the data described in the results and supported by quotes from the participants also helps to enhance the ability of others to understand the interpretations from the data. The health professionals in this study may have been those who are more comfortable talking about HPV, so it is possible that additional themes may have arisen in those who do not talk about HPV, as these were difficult to sample. Conversely, the health professionals in this sample may have been interested in receiving more information about HPV in the context of HNC and might have been hoping to learn something through their participation. Participants may also have personal biases which could influence the discussion of sensitive topics such as sexually transmitted infections. Comparisons were not able to be drawn between the different professional groups because of small numbers, but this could be an important avenue of future research. Patients' views were not explored in this study, so caution is also needed when interpreting the data about patients' concerns, as these are all from the perspective of the health professionals.

6.6 Conclusion

This exploratory study has gained insight into the challenges faced by health professionals caring for HNC patients. The demographic characteristics of patients with HPV-OSCC present new challenges for health professionals in terms of the questions being asked, the factors important to the patients, and their rehabilitation and treatment needs. Experiences among health professionals differed, suggesting a need for clinical guidance for communication about HPV in this context to ensure that patients are receiving consistent messages. Due to the

exploratory nature of these findings, it is important to use these to develop larger quantitative studies, which leads into my next study in chapter 7. It is also important to carry out research with patients to explore how being diagnosed with HPV-OSCC impacts them, which leads to my study conducted in chapter 8.

CHAPTER 7. DISCUSSING HPV WITH PATIENTS: A SURVEY OF HEALTH PROFESSIONALS IN THE UK AND IRELAND (STUDY 4)

7.1 Introduction

The findings from chapter 6 alongside other qualitative research conducted with health professionals suggests that many of the psychological and communication challenges associated with cervical HPV may also apply in the head and neck cancer (HNC) context (Daley et al., 2011). Research has shown sexual behaviour through both oral sex and open mouth kissing are associated with acquisition of oral HPV infection (D'Souza et al., 2009) and both a USA study (Daley et al., 2011), and my findings from chapter 6 (Dodd, Marlow, & Waller, 2016), suggested these health professionals find it difficult to talk to their patients about their HPV-OSCC due to the sexual nature of the acquisition of the virus. Some health professionals in chapter 6 also expressed concern that their knowledge about the role of HPV in OSCC was limited and that this impacted their ability to respond to some of the questions that were being asked by patients. For the reasons stated in the previous chapter, the term OSCC will be used in this chapter, unless referring to specific studies and to the survey, where HNC was used to encompass all anatomical sites.

Current evidence suggests that not all health professionals involved in the diagnosis and treatment of HNC are aware of the risk factors for the disease, in particular the link with HPV. As the systematic review in chapter 4 showed, knowledge of the association between HPV and HNC among health professionals ranges from 26-88% in dentists (Maybury et al., 2012; Reed et al., 2010) and 34-91% in other medical professionals (Alami et al., 2013; Malloy et al., 2013). None of this previous research was conducted in the UK. A previous study with oral health professionals in the USA assessed knowledge of HPV and attitudes to discussing HPV (Daley et al., 2011) and found a range in knowledge of HPV-related HNC from complete lack of knowledge, to understanding of some details, and that they wanted more knowledge and training to aid in communicating with patients.

There is no available literature focusing on attitudes of medical professionals when discussing HPV in the context of oropharyngeal squamous cell carcinoma (OSCC), but there has been a great deal of previous work focusing on health professionals' attitudes towards the HPV vaccination. Studies exploring HPV in the context of the HPV vaccination are referred to here to provide some examples of barriers to discussing HPV. Studies have found the discussion of the sexual nature of HPV as a barrier to physicians recommending the HPV vaccination (Bynum et al., 2014; Daley et al., 2010). In contrast, those who routinely discuss sexual health issues and who feel comfortable doing so, are more likely to recommend the HPV vaccine to their patients (Allison et al., 2013; McCave, 2010), showing a clear need for an intervention around sexual health which aims to improve patient-provider communication about the topic (Bynum et al., 2014).

Previous research around the HPV vaccination has found that those health professionals with greater knowledge about HPV and the HPV vaccination are more likely to recommend it (Holder, Katzenellenbogen, & Middleman, 2013). Doctors have previously reported self-rated knowledge as an important determinant of their willingness to recommend the HPV vaccination (Hopkins, Wood, West, & Darling, 2009). These findings demonstrate that knowledge is an important component with regard to health professionals being willing to discuss HPV and is important for answering patients' questions, which could also apply in the OSCC context.

The key messages to discuss with patients about HPV that were raised by health professionals in chapter 6 were to normalise HPV by emphasising its high prevalence, relating it back to its relationship with cervical cancer and explaining that HPV is a result of normal sexual behaviour. Explaining to patients that there is no need to change their behaviour and that the prognosis for HPV-OSCC patients is much better than other forms of HNC were other key messages.

Qualitative studies, such as my previous study in chapter 6, are limited in their ability to assess how widespread these concerns are. Qualitative studies also do not produce measureable results to enable comparisons across groups and relationships among variables. Therefore, this study aimed to assess knowledge of HPV and experiences of discussing HPV with patients among a larger sample of different health professionals involved in the treatment of OSCC. This study contributes to the sixth research question of this thesis:

- 6) What are the experiences and attitudes of different groups of health professionals in the UK and Ireland who care for patients with HPV-OSCC?

7.2 Methods

7.2.1 Study Design

This was a cross-sectional survey completed online through the platform Opinio or on paper.

7.2.2 Ethics

This study was approved by the UCL Research Ethics Committee, reference 4577/003 (Appendix 7.1).

7.2.3 Participants

Health professionals [surgeons, oncologists, specialist nurses and allied health professionals (all other health professionals including speech and language therapists, dietitians and staff nurses)] in roles working directly with HNC patients in the UK and/or Ireland completed a survey.

7.2.4 Recruitment

Health professionals were recruited through several of the NHS cancer networks (e.g. London Cancer Alliance) (Appendix 7.2) and other professional organisations (National Cancer Research Institute, National Cancer Intelligence Network), as well as through existing contacts in the NHS and previous research studies (Table 7.1). NHS cancer networks were contacted if a contact name was available and delegate lists available from relevant conferences were used to help provide the names of HNC health professionals and email addresses were sourced for these names where possible. When contacting health professionals directly through email, snowballing techniques were used as they were asked to disseminate it within their teams. Health professionals were also recruited at three HNC specific conference days where data were collected using a paper questionnaire. Participants were told that they were consenting to their data being used by completing the survey (Appendix 7.3) and participants read a short debrief at the end of the survey (Appendix 7.4). Where possible, reminders were sent to those who received the online link to the survey two and four weeks after the initial email. A sample

size calculation with $\alpha=0.05$ and a power of 0.8, suggested that for the chi-square tests 220 participants were needed to detect a medium effect size of $r=0.3$. The chi-square tests were conducted to test for differences in experience and attitudes across the five health professionals groups: surgeons, oncologist, specialist nurses, speech and language therapists and 'other' health professionals.

Table 7.1: Details of the sources of recruitment

Recruitment source	Details about the source	Which health professionals	Online/paper
NHS Cancer networks (e.g. London Cancer Alliance)	Strategic Clinical Networks focus on priority service areas to bring about improvement in the quality and equity of care and outcomes of their population, both now and in the future. There are 14 cancer networks across England and Wales. Three of the 14 networks sent out information and the link to the survey.	All disciplines	Online
National Cancer Research Institute	The National Cancer Research Institute is a UK-wide partnership between research funders working together to make faster progress against cancer.	All disciplines	Online
National Cancer Intelligence Network (NCIN)	The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.	All disciplines	Online
Head and Neck Cancer Masterclass	This masterclass offered the opportunity for all professional groups working with head & neck cancer patients to come together to hear about the latest developments in treatment and care and to discuss issues of mutual interest. The meeting was attended by around 80 – 100 health professionals from across the multi-disciplinary team.	Predominantly Clinical Nurse Specialists, Speech & Language Therapists, Radiographers and Dietitians	Paper
Joint Meeting of the Northern and Southern Clinical Excellence Networks for Head and Neck Cancer	The purpose of this joint study day was to enhance participants' knowledge of HPV in the context of head and neck cancer, critical issues in the management of acute and late swallowing toxicities and clinical trials aiming to ascertain optimal treatment delivery aimed at minimising late dysphagia.	Predominantly Clinical Nurse Specialists, Speech & Language Therapists, Radiographers and Dietitians	Paper
Head and Neck Study Day – The Royal Marsden Hospital	This meeting explored the issues surrounding cutaneous malignancy of the head and neck. It included: evidence-based lectures that focused on the management of a variety of skin and adnexal cancers including non-invasive diagnostic testing,	Specialist Registrars and Consultants in Head and Neck / Maxillofacial / ENT / Plastic Surgery, Dermatologists,	Paper

	the assessment of regional nodes, the role of adjuvant treatment and targeted therapies, a discussion on how surgeon-level reporting might influence the delivery of head and neck cancer care.	Clinical and Medical Oncologists, Pathologists and all members of the extended Head and Neck Team	
British Association of Head and Neck Oncologists Annual Scientific Meeting 2015	Email addresses were searched for online for the names on the delegate lists.	Clinical oncologists, surgeons, clinical nurse specialists, maxillofacial oncologists, ENT	Online
British Association of Oral and Maxillofacial Surgeons – list of hospital units	Email addresses were searched for online for the names on the delegate lists.	Oral and Maxillofacial Surgeons	Online
A list of contacts from a researcher in Ireland	A researcher who works closely with my research group provided a list of health professionals who had been involved in previous research with them and were happy to be involved in future research. All health professionals were emailed.	Clinical oncologists, surgeons, clinical nurse specialists, maxillofacial oncologists, ENT	Online
Multidisciplinary teams (MDT)	Some health professionals distributed it to their hospital MDT	All disciplines	Online
British Association of Head and Neck Oncology Nurses website	The study was advertised on the website	Head and neck cancer oncology nurses	Online

7.2.5 Materials and Measures

Awareness of HPV

Health professionals were asked to respond 'yes', 'no' or 'don't know' to the question 'Have you ever heard of HPV?' Health professionals were also asked, 'Have you ever looked for any information on human papillomavirus (HPV) and head and neck cancer?' (yes; no; don't remember) and 'If yes, where have you looked?' (other colleagues; internet; journals; media; conferences; professional organisations; medical textbooks; other; not applicable).

Knowledge about HPV

Health professionals were asked to respond 'true', 'false' or 'don't know' to seven selected items from a validated measure of HPV knowledge including, 'HPV often has no visible signs or symptoms' and 'Having many sexual partners increases the risk of getting HPV' (Waller, Ostini, Marlow, McCaffery, & Zimet, 2013). This measure includes 16 items, but these items were selected because they were about HPV in general and were not specific to genital HPV. An additional five items specifically about HPV and HNC were included, such as 'The oral tongue is the principal head and neck cancer site associated with HPV' from a previous study (Malloy et al., 2013) which measured knowledge of HPV and HNC in head and neck surgeons. The reliability of the 12 item scale in this study sample was questionable ($\alpha=0.62$) (George & Mallery, 2003).

Experiences of discussing HPV with patients

Four items assessed health professionals' experiences of informing HNC patients about HPV: 'Thinking about the patients you treat with HPV-related head and neck cancer, how many of them have you told that their cancer was caused by HPV?' (all; most; some; none) and 'If you have informed a patient about their HPV status, have you discussed HPV in detail with a patient?' (yes; no; not sure). Health professionals were also asked, 'Generally, how willing are you to discuss HPV with your patients in the future?' (not at all willing; not very willing; neither willing or unwilling; somewhat willing; very willing) and 'If you discuss HPV during consultations, who usually initiates the discussion?' (myself; patient; sometimes me, sometimes the patient; other; not applicable). These items were developed from the findings in chapter 6.

Attitudes to discussing HPV with patients

Thirty-two items assessed how health professionals think and feel about discussing HPV with patients', such as 'Discussing HPV with patients is important' and 'I am confident that I can initiate a discussion about HPV with a patient', about discussing HPV with a patients' partner present, such as 'I would use a different approach if the patient was alone', about their attitudes to discussing HPV such as, 'I don't want to pass judgement on patients' sexual behaviour' and how it would be helpful for them to keep up-to-date with the latest information about HPV such as 'Have regular team updates'. Responses to these questions were on a 5-point likert scale (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree). These items

were developed based on the findings from chapter 6 and existing literature (Malloy et al., 2013; McSherry et al., 2012).

Socio-demographics

Health professionals completed measures assessing their demographic and professional background developed for this study. These included: age, sex, country of training, 'Did you train in the UK?' (yes; no); 'If no, where did you train?' (open response); profession, 'What is your profession?' (surgeon; oncologist; specialist nurse; other); years in profession, 'How many years have you been practicing in this profession?' (open response) and their main place of work (hospital; hospice; rehabilitation centre; other).

The full questionnaire can be found in Appendix 7.5.

7.2.6 Analysis

Descriptive statistics were analysed for each of the measures assessing awareness of HPV (n/%), knowledge of HPV (n/%), experiences of discussing HPV (n/%), attitudes and beliefs of health professional groups (n/%) and socio-demographics (n/%). Chi-square tests were used to compare individual items from the knowledge scale across health professional groups and ANOVA was used to compare across health professional groups for total scale score for knowledge of HPV and for their scores on each factor.

Factor analysis was run with the items tapping into attitudes and beliefs to reduce the large number of items into factors which could be compared across groups more easily and meaningfully. Cronbach's alpha was calculated for each factor. Pearson's correlations were run to explore the relationships between the factors produced in the factor analysis. Independent t-tests were used to compare differences on the factors by gender.

When converting the paper-based questionnaire into an online version, the item 'I am confident that I can reassure patients that HPV is a result of normal sexual behaviour' was missed. This error was only noticed after 85 responses had already been received through the online survey, but was immediately rectified. In addition, the list of information sources in the online questionnaire included 'medical textbooks' as a response, whereas the paper-based version did not and so responses for this are only available for 193 participants.

7.2.7 Missing data

Using an online survey meant that the questions could be set as being mandatory and participants could not move onto the next question unless they had answered each question. This meant for the participants who responded through the online survey (n=193), there were no missing data. For the remaining participants (n=67) who completed the paper survey, there was very little missing data (less than 1%) on all variables. Cases where missing values occurred were coded as missing and included in the analyses. An exception to this included the variable mentioned above which had missing responses for 85 participants online. This variable was included in the descriptive analyses, but excluded from the factor analysis.

7.3 Results

7.3.1 Sample characteristics

The response rate is unknown, as the survey was sent through a number of cancer networks, organisations and also by personal email. The size of the cancer networks and organisations was not possible to track and some health professionals may have received the survey from multiple sources. I was therefore unable to calculate an accurate denominator and do not have any data available for those who chose not to respond to the survey. 260 health professionals from the UK and Ireland completed the survey. Table 7.2 shows the sample characteristics. The majority of the sample were female (59.6%, n=155), had trained in the UK (91.2%, n=237) and mostly worked in a hospital (97.3%, n=253). Surgeons were the profession most represented in the sample (36.9%, n=96). Some examples of professionals in the 'other' group of health professionals include dieticians, staff nurses, research nurses and radiographers (Table 7.3).

Table 7.2: Sample characteristics

Characteristic	Number of participants (n=260)
Age [median(range)]	45 (21-66)
Sex [n(%)]	
Male	105 (40.4)
Female	155 (59.6)
Profession [n(%)]	
Surgeon	96 (36.9)
Oncologist	28 (10.8)
Specialist nurse	40 (15.4)
Speech and language therapist	59 (22.7)
Other*	37 (14.2)
Years practising in profession [median(range)]	17 (0-45)
Trained in the UK [n(%)]	
Yes	237 (91.2)
No	23 (8.8)
Main place of work [n(%)]	
Hospital	253 (97.3)
Other	7 (2.7)

*includes dietitians, radiographers, staff nurses, research nurses (Table 7.3)

The median age of the sample was 45, ranging from 21 years through to 66 years. Health professionals had worked in their profession for a median of 17 years, which ranged across the sample from 0 to 45 years. Almost all (99.2%) had heard of HPV and 94.2% said they had looked for information about HPV and HNC. The internet, medical journals and other colleagues were the top three places health professionals looked for information (Figure 7.1).

Table 7.3: Specific health professions in the ‘other’ group

Professions in the ‘other’ group	Number of participants (n=37)
Dieticians	7
Staff nurse	7
Therapy radiographer	4
Oral medicine	3
Dentist	3
Research nurse	2
Allied health professional (did not specify)	2
Unknown	2
Specialist radiographer	1
Research radiographer	1
GP	1
Radiologist	1
Clinical psychologist	1
Dermatologist	1
Dental nurse specialist	1

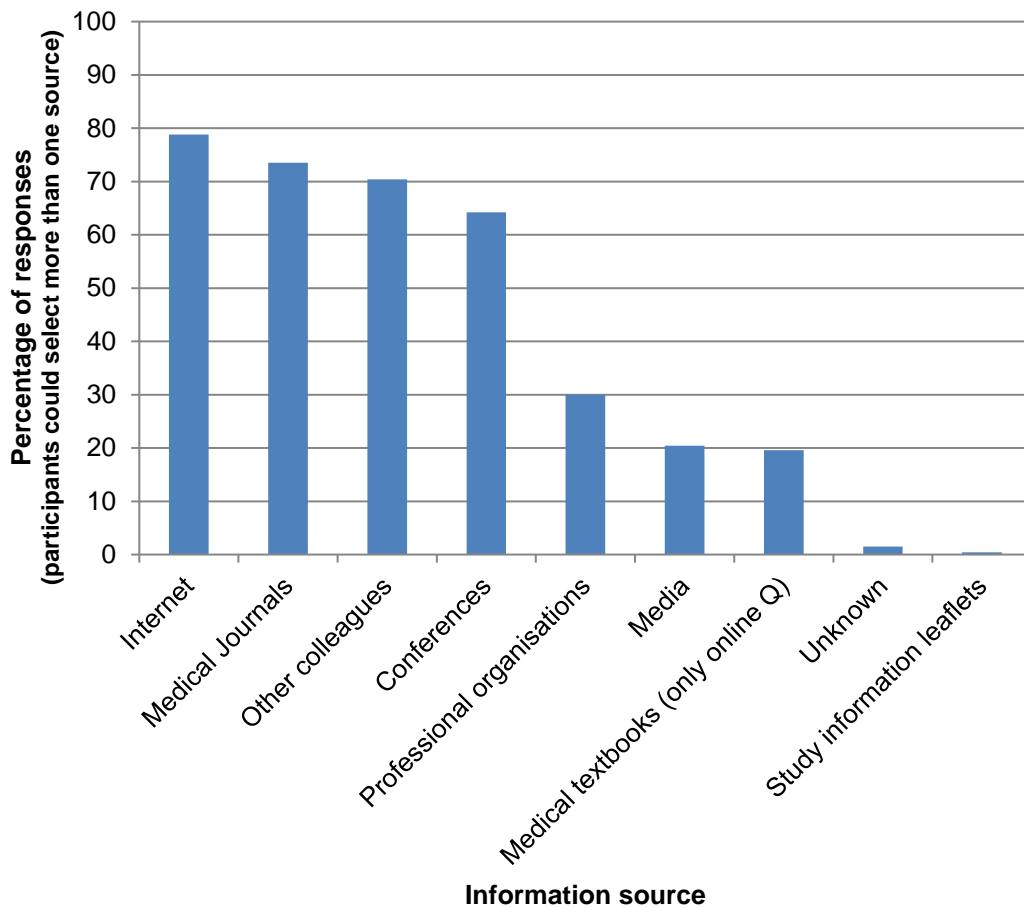


Figure 7.1: Frequency of information sources searched for HPV and head and neck cancer

7.3.2 Knowledge of HPV

The proportion of respondents giving the correct answer to each individual knowledge item is shown in Table 7.4, with statistical tests and p values, indicating differences by profession.

Across all health professional groups, knowledge of HPV was high. Most participants correctly answered the item 'a person could have HPV for many years without knowing it' (97.7%, n=253), while the item 'HPV usually goes away without needing any treatment' was answered correctly by the fewest number of participants (45.8%, n=119).

The mean knowledge score in the whole sample was 9.97 out of a possible 12. Total knowledge score was highest in oncologists, followed by surgeons, specialist nurses, speech and language therapists and the 'other' group of health professionals ($F(4,246) = 10.48, p < 0.001$). Surgeons had a significantly higher mean knowledge score than the 'other' group of health professionals ($p = 0.001$) and speech and language therapists ($p < 0.001$); and oncologists had a significantly higher mean score than specialist nurses ($p = 0.017$), speech and language therapists ($p < 0.001$) and the 'other' group of health professionals ($p < 0.001$).

For four of the items (Having many sexual partners increases the risk of getting HPV; the oral tongue is the principal head and neck cancer site associated with HPV; HPV is a relatively uncommon sexually transmitted infection; most patients with oral HPV experience symptoms of the infection), a greater proportion of surgeons and oncologists answered these correctly compared to speech and language therapists and the 'other' group of health professionals and for two of the items (HPV often has no visible signs or symptoms; HPV is very rare), a greater proportion of surgeons, oncologists and nurses answered these correctly compared to speech and language therapists and the 'other' group of health professionals.

Table 7.4: Correct responses (n/%) to individual knowledge of HPV items amongst all professional groups (n=260)*

	Overall	Surgeons (n=96)	Oncologists (n=28)	Specialist nurses (n=40)	Speech and language therapists (n=59)	Other (n=37)	χ^2 (p value)
HPV often has no visible signs or symptoms	239 (91.9)	91 (94.8)	28 (100)	38 (95.0)	49 (83.1)	33 (89.2)	10.66 (0.031)
HPV is very rare (F)	244 (93.8)	94 (97.9)	28 (100)	38 (95.0)	52 (88.1)	32 (86.5)	11.48 (0.022)
A person could have HPV for many years without knowing it	253 (97.7)	95 (99.0)	27 (96.4)	38 (97.4)	56 (94.9)	37 (100)	3.77 (0.438)
Having many sexual partners increases the risk of getting HPV	230 (88.8)	91 (94.8)	28 (100)	30 (76.9)	49 (83.1)	32 (86.5)	14.69 (0.005)
HPV can cause cervical cancer	253 (97.3)	96 (100)	28 (100)	39 (97.5)	55 (93.2)	35 (94.6)	8.24 (0.083)
HPV usually goes away without needing any treatment	119 (45.8)	47 (49.0)	17 (60.7)	18 (45.0)	25 (42.4)	12 (32.4)	5.85 (0.211)
Most sexually active people will get HPV at some point in their lives	159 (61.9)	62 (65.3)	21 (75.0)	25 (65.8)	31 (52.5)	20 (54.1)	5.89 (0.207)
HPV can cause oral cancer	240 (92.7)	85 (88.5)	27 (96.4)	38 (97.4)	53 (89.8)	37 (100)	7.92 (0.095)
The oral tongue is the principal head and neck cancer site associated with HPV (F)	191 (93.7)	83 (86.5)	26 (92.9)	24 (60.0)	39 (66.1)	19 (52.8)	27.15 (<0.001)
HPV is a relatively uncommon sexually transmitted infection (F)	201 (78.2)	84 (87.5)	27 (96.4)	26 (68.4)	40 (67.8)	24 (66.7)	19.02 (0.001)
HPV is associated with a much improved prognosis for patients with head and neck cancer	229 (88.1)	87 (90.6)	27 (96.4)	34 (85.0)	53 (89.8)	28 (75.7)	8.41 (0.078)
Most patients with oral HPV experience symptoms of the infection (F)	223 (85.8)	91 (94.8)	27 (96.4)	34 (85.0)	42 (71.2)	29 (78.4)	20.96 (<0.001)
Total knowledge score: mean(standard deviation)	9.97 (1.82)	10.48 ^{ab} (1.32)	11.11 ^{cde} (0.83)	9.74 (1.85) ^c	9.22 (2.06) ^{bd}	9.14 (2.2) ^{ae}	F(4,246)=10.48, p<0.001

*n varies slightly between items due to missing data; (F) indicates items for which 'false' is the correct response. All other items are true; ^{abcde} indicates which groups are significantly different from each other in post hoc tests.

7.3.3 Experiences of discussing HPV

Across three of the items asking about the participants' experiences of discussing HPV with their patients, a greater proportion of surgeons, oncologists and specialist nurses had more experience in telling their patients that their cancer was caused by HPV ($\chi^2 (12)=78.49$, $p<0.001$), had discussed this in detail with their patients ($\chi^2 (8)=23.48$, $p=0.003$) and they were more willing to discuss HPV with their patients in the future ($\chi^2 (16)=51.79$, $p<0.001$) compared to the speech and language therapists and the 'other' group of health professionals.

Of the health professional groups, a greater proportion of oncologists reported initiating the discussion about HPV themselves (67.9%), followed by surgeons (54.8%) and specialist nurses (25.7%; $\chi^2 (12)=95.94$, $p<0.001$). In those speech and language therapists who had discussed HPV with patients ($n=40$), 55% ($n=22$) reported that the patient had initiated the discussion. All health professional groups reported that sometimes it was them who initiated the conversation and sometimes it was the patient.

7.3.4 Attitudes and beliefs about discussing HPV

The results of chi-square tests for each individual survey item are included in Appendix 7.6. The questionnaire was designed to measure attitudes about discussing HPV with patients and I was interested in which latent variables may contribute to attitudes to discussing HPV. A principal components analysis (PCA) was conducted with orthogonal rotation (Varimax) (Field, 2009). PCA was conducted as this was an exploratory factor analysis and the goal was to reduce the larger set of variables into a smaller set of new variables. The conclusions from PCA are restricted to the sample collected and therefore may not be generalisable to other sample populations. Orthogonal rotation (Varimax) was used as the factors were expected to not be correlated with each other. The item, 'I am confident that I can reassure patients that HPV is a result of normal sexual behaviour' was not included in the analysis as there was missing data (as explained in section 7.2.6). After checking the correlation matrix, two items were removed (I would use a different approach than if the patient was alone; I don't want to pass judgement on patients' sexual behaviour) from the analysis due to low correlations with other items.

PCA was conducted primarily and principal axis factoring was conducted to test the content validity of the factors. The analysis was also conducted forcing the items into five factors and

the items in each factor were assessed to examine whether they made sense in the factors they had been forced into, but the factors did not make as much sense as when loaded onto seven factors. Running the factor analysis both with orthogonal rotation (varimax) and oblique rotation (direct oblimin) also allowed the component correlation matrix to be assessed against whether the factors in the analysis were correlated or uncorrelated. As the component correlation matrix showed low correlations between the factors (Appendix 7.7), an orthogonal rotation was deemed appropriate. Cronbach's alpha was run on each factor subscale.

A PCA was conducted on 29 items with orthogonal rotation (Varimax) and found seven factors with eigenvalues over Kaiser's criterion of 1 (Kaiser, 1960) and in combination explained 63.03% of the variance (Table 7.5). The scree plot showed inflexions that would justify retaining these seven factors (Appendix 7.8). The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis, KMO=0.826. Bartlett's Test of Sphericity ($\chi^2(406)=3241.44$, $p<0.001$) indicated that the correlations were sufficiently large for PCA. An initial analysis was run to obtain eigenvalues for each component in the data. The items that cluster on the same factor suggest that factor 1 represents confidence in discussing HPV ($\alpha=0.89$), factor 2 represents ways to facilitate the discussion of HPV ($\alpha=0.81$), factor 3 represents negative attitudes to discussing HPV ($\alpha=0.75$), factor 4 represents positive attitudes to discussing HPV ($\alpha=0.76$), factor 5 represents personal barriers for health professionals not discussing HPV ($\alpha=0.71$), factor 6 represents the need for more information ($\alpha=0.64$) and factor 7 represents attitudes to talking about sexual relationships ($\alpha=0.83$). All items had a factor loading of greater than 0.45 in their respective factors (Table 7.5). The item 'I don't have enough information on HPV-related head and neck cancer' was reversed before computing the factors and calculating the mean of the items that loaded onto each of the factors, which was then taken as the score and reported in Table 7.6.

Factor 1: Confidence in discussing HPV

There were five items loading onto factor 1, with an overall mean score of 3.41 (scale 1-5) and standard deviation of 0.83, suggesting overall health professionals are fairly confident in discussing HPV. There was a significant positive correlation between knowledge ($M=9.97$, $SD=1.82$) and confidence ($M=3.41$, $SD=0.83$), $r=0.435$, $p<0.001$ (Table 7.7), and between years practising in their profession ($M=18.11$, $SD=9.62$) and confidence ($M=3.41$, $SD=0.83$), $r=0.138$,

$p=0.027$. There was a significant main effect across professional groups in their confidence talking about HPV ($F(4,253) = 22.80, p<0.001$; Table 7.6). Post hoc tests (Appendix 7.9) found significantly lower average scores in confidence in both speech and language therapists and health professionals in the 'other' group, compared to surgeons, oncologists and specialist nurses. Confidence was also significantly higher in males than in females ($t(254.56) = 6.26, p<0.001$; Table 7.8).

Factor 2: Ways to facilitate the discussion of HPV

There were four items loading onto factor 2, with an overall mean score of 3.97 and standard deviation of 0.56, suggesting health professionals mostly agreed with the methods suggested as ways to facilitate the discussion of HPV. A significant main effect was found across health professional groups in their agreement to the methods suggested for facilitating the discussion of HPV ($F(4,254) = 12.01, p<0.001$; Table 7.6). Speech and language therapists and specialist nurses had greater average scores for methods to facilitate the discussion of HPV, indicating they agreed more strongly with the methods suggested. Post hoc tests found these scores to be significantly higher for both these health professional groups than in surgeons and oncologists and between the health professionals in the 'other' group and speech and language therapists (Appendix 7.9).

Female health professionals had greater average scores for ways to facilitate the discussion of HPV ($t(257) = -5.63, p<0.001$; Table 7.8), indicating they agreed more strongly with the methods suggested to facilitate the discussion of HPV than men.

Table 7.5: Summary of PCA results for the survey (n=254)

Item	Rotated factor loadings	Eigenvalue (% of variance)	α
Confidence in discussing HPV		5.91 (20.4)	0.89
I am confident that I can deal with patients' questions and concerns when I talk to them about HPV	0.848		
I am confident that I can explain HPV in a way that patients can understand	0.848		
I am confident about initiating a discussion about HPV with a patient	0.836		
I would feel confident discussing the transmission of HPV	0.731		
I don't have enough information on HPV-related head and neck cancer	-0.614		
Ways to facilitate discussing HPV		5.07 (17.5)	0.81
Have regular feedback of experiences with patients from colleagues	0.784		
Have regular team updates	0.777		
Attend further training	0.754		
Attend conferences	0.733		
Negative attitudes to discussing HPV		1.85 (6.4)	0.75
I don't think patients want to know about HPV-related head and neck cancer	0.756		
I don't see any reason to discuss HPV with patients	0.731		
It is not necessary to tell patients whether they have HPV because it doesn't change their clinical management	0.669		
My patients are not concerned about the cause of their cancer	0.657		
It is not necessary to tell patients that they have HPV because there's no implications for behaviour	0.556		
Positive attitudes to discussing HPV		1.63 (5.6)	0.76
It is helpful for the patient to understand the cause of their head and neck cancer	0.706		
Information about HPV is reassuring to patients	0.696		
It is important to convey the positive prognosis of HPV-related head and neck cancer to patients	0.640		
Discussing HPV with patients is important	0.610		
It is important to provide accurate information about HPV to the patient	0.563		
Personal barriers to discussing HPV		1.5 (5.2)	0.71
Talking to a patient about HPV is embarrassing	0.823		
Talking about HPV with a patient is not easy because it's about their sexual behaviour	0.792		
I don't have enough time to discuss HPV-related head and neck cancer	0.498		
I am not used to talking about sexual health with my patients	0.466		

Item	Rotated factor loadings	Eigenvalue (% of variance)	α
Need for more information		1.28 (4.4)	0.64
HPV-related head and neck cancer is an evolving area so it's hard to keep up-to-date	0.655		
Having a clear plan of what I was going to say would help me discuss HPV with patients	0.592		
I might not have all the answers to patients' questions about HPV-related head and neck cancer	0.585		
Having a leaflet to pass onto patients would help me discuss HPV with them	0.524		
Attitudes to talking about sexual relationships		1.05 (3.6)	0.83
I would feel comfortable talking about infidelity if this was raised	0.815		
I would feel comfortable talking about their sexual relationship	0.770		

Table 7.6: Average score (mean/SD; 1-5) for factors reflecting attitudes and beliefs about discussing HPV with oropharyngeal cancer patients

	Surgeons (n=96)	Oncologists (n=28)	Specialist nurses (n=40)	Speech and language therapists (n=59)	Other (n=37)	F (p value)
Confidence in discussing HPV	3.74 (0.65) ^{ab}	3.88 (0.58) ^{cd}	3.59 (0.74) ^{ef}	2.74 (0.82) ^{ade}	3.10 (0.80) ^{bcd}	22.80 (<0.001)
Ways to facilitate discussion of HPV	3.78 (0.51) ^{ab}	3.70 (0.57) ^{cd}	4.24 (0.55) ^{ac}	4.24 (0.46) ^{bde}	3.91 (0.52) ^e	12.01 (<0.001)
Negative attitudes to discussing HPV	1.98 (0.53) ^a	1.90 (0.47)	1.66 (0.55) ^{abc}	2.00 (0.42) ^c	2.02 (0.60) ^b	3.49 (0.009)
Positive attitudes to discussing HPV	4.12 (0.50) ^a	4.10 (0.46) ^b	4.52 (0.48) ^{abc}	4.26 (0.42)	4.18 (0.48) ^c	5.59 (<0.001)
Personal barriers to discussing HPV	2.69 (0.71) ^{ab}	2.76 (0.71)	2.30 (0.70) ^{acd}	3.05 (0.66) ^{bd}	2.81 (0.70) ^c	6.92 (<0.001)
Need for more information	3.69 (0.52) ^a	3.66 (0.60) ^b	3.95 (0.38)	4.18 (0.41) ^{abc}	3.77 (0.64) ^c	9.83 (<0.001)
Attitudes to talking about sexual relationships	2.79 (0.94) ^a	3.11 (0.97)	3.46 (0.81) ^{abc}	2.57 (0.92) ^b	2.82 (0.72) ^c	6.76 (<0.001)

n for items varies slightly due to missing data

^{abcdef} indicates across rows which groups are significantly different from each other in post hoc tests (Appendix 7.9)

Table 7.7: Correlation matrix for all factors and total knowledge score and willingness to discuss HPV

	Confidence in discussing HPV	Ways to facilitate discussion of HPV	Negative attitudes to discussing HPV	Positive attitudes to discussing HPV	Personal barriers to discussing HPV	Need for more information	Attitudes to talking about sexual relationships	Knowledge	Willingness to discuss HPV
Confidence in discussing HPV	1								
Ways to facilitate discussion of HPV	-0.181**	1							
Negative attitudes to discussing HPV	-0.097	-0.235**	1						
Positive attitudes to discussing HPV	0.132*	0.307**	-0.508**	1					
Personal barriers to discussing HPV	-0.484**	0.050	0.244**	-0.251**	1				
Need for more information	-0.415**	0.431**	-0.213**	0.156*	0.294**	1			
Attitudes to talking about sexual relationships	0.473**	-0.066	-0.133*	0.193**	-0.485**	-0.206**	1		
Knowledge	0.435**	-0.107	-0.071	-0.033	-0.164**	-0.154*	0.183**	1	
Willingness to discuss HPV	0.582**	-0.059	-0.232**	0.201**	-0.456**	-0.149*	0.381**	0.347**	1

*correlation is significant at the 0.05 level (2-tailed)

**correlation is significant at the 0.01 level (2-tailed)

Table 7.8: Independent t-tests of factors by gender

Factor	Males (mean;SD)	Females (mean;SD)	Significance
Confidence in discussing HPV	3.76 (0.64)	3.18 (0.87)	<0.001
Ways to facilitate discussion of HPV	3.74 (0.54)	4.12 (0.52)	<0.001
Negative attitudes to discussing HPV	1.98 (0.54)	1.90 (0.51)	0.246
Positive attitudes to discussing HPV	4.12 (0.48)	4.28 (0.48)	0.008
Personal barriers to discussing HPV	2.71 (0.74)	2.76 (0.72)	0.604
Need for more information	3.68 (0.53)	3.96 (0.52)	<0.001
Attitudes to talking about sexual relationships	2.80 (0.96)	2.93 (0.91)	0.292

Factor 3: Negative attitudes to discussing HPV

There were five items loading onto factor 3, with an overall mean score of 1.93 and standard deviation of 0.53, suggesting health professionals disagreed with the items about why they would not discuss HPV. Negative attitudes for not discussing HPV differed significantly across the health professional groups ($F(4,252) = 3.49, p=0.009$; Table 7.6). Post hoc tests found surgeons, the 'other' group of health professionals and speech and language therapists to have significantly higher average scores for this factor than specialist nurses, indicating they had more negative attitudes towards discussing HPV (Appendix 7.9). No significant differences were found across gender and negative attitudes to discussing HPV (Table 7.8).

Factor 4: Positive attitudes to discussing HPV

There were five items loading onto factor 4, with an overall mean score of 4.22 and standard deviation of 0.49, suggesting health professionals had positive attitudes towards discussing HPV. The factor representing positive attitudes to discussing HPV were significantly different across professional groups ($F(4,254) = 5.59, p<0.001$; Table 7.6), with scores being higher in specialist nurses than surgeons, oncologists and the 'other' health professional group (Appendix 7.9).

Female health professionals scored higher than male health professionals ($t(257)=-2.68$, $p=0.008$; Table 7.8).

Factor 5: Personal barriers to discussing HPV

There were four items loading onto factor 5, with an overall mean score of 2.74 and standard deviation of 0.73, suggesting some level of disagreement from health professionals about personal barriers to discussing HPV. Personal barriers represented in the factor included talking about HPV being embarrassing and HPV not being easy to talk about because it's about their sexual behaviour. A significant main effect was found ($F(4,253) = 6.92$, $p<0.001$; Table 7.6), with surgeons, speech and language therapists and the 'other' group reporting significantly higher scores for personal barriers than specialist nurses and surgeons reporting significantly lower scores for personal barriers than speech and language therapists (Appendix 7.9). No significant gender differences were found for this factor (Table 7.8).

Factor 6: The need for more information

There were four items loading onto factor 6, with an overall mean score of 3.85 and standard deviation of 0.54, suggesting health professionals agreed with the need for further information about HPV. The factor representing the need for more information showed a significant main effect between health professional groups ($F(4,254) = 9.83$, $p<0.001$; Table 7.6). Speech and language therapists had a significantly greater need for information than surgeons, oncologists and the 'other' group of health professionals (Appendix 7.9).

Females expressed a greater need for information than men ($t(257)=-4.30$, $p<0.001$; Table 7.8).

Factor 7: Attitudes to talking about sexual relationships

There were two items loading onto factor 7, with an overall mean score of 2.88 and standard deviation of 0.93, suggesting some level of disagreement with these items and that health professionals are not comfortable talking about sexual relationships. The final factor which represented health professionals' attitudes in talking about patients' sexual relationships, showed a significant main effect across health professional groups ($F(4,254) = 6.76$, $p<0.001$; Table 7.6), with specialist nurses being significantly more comfortable than surgeons, the 'other'

health professional group and speech and language therapists (Appendix 7.9). No significant gender differences were found for this factor (Table 7.8).

Correlations among factors and other variables

The correlation matrix (Table 7.7) shows significant associations between most of the factors. Most notably, knowledge was significantly positively associated with confidence ($r=0.435$, $p<0.001$), reasons it is important to discuss HPV ($r=0.132$, $p=0.034$), willingness to discuss HPV in the future ($r=0.347$, $p<0.01$) and negatively associated with personal barriers to discussing HPV ($r=-0.164$, $p<0.01$). Willingness to discuss HPV in the future was positively associated with confidence ($r=0.582$, $p<0.01$), reasons it is important to discuss HPV ($r=0.201$, $p<0.01$), comfort in talking about sexual relationships ($r=0.381$, $p<0.01$) and negatively associated with personal barriers to discussing HPV ($r=-0.456$, $p<0.01$). Personal barriers to discussing HPV were also negatively associated with confidence ($r=-0.484$, $p<0.01$), reasons it is important to discuss HPV ($r=-0.251$, $p<0.01$), comfort in talking about sexual relationships ($r=-0.485$, $p<0.01$) and positively associated with the need for more information ($r=0.294$, $p<0.01$).

7.4 Discussion

This study measured knowledge, attitudes and beliefs about discussing HPV-OSCC with patients among health professionals in the UK and Ireland. Almost all (99.2%) had heard of HPV and 94.2% said they had looked for information about HPV and HNC. The internet, medical journals and other colleagues were the top three places health professionals looked for information, supporting findings from previous research (Daley et al., 2011). Oncologists had the greatest knowledge, followed by surgeons, specialist nurses, speech and language therapists and the health professionals in the 'other' group, demonstrating a need to increase knowledge among allied health professionals. The item 'HPV usually goes away without needing any treatment' was the item answered correctly by the fewest number of participants overall and suggests health professionals may incorrectly believe that HPV always needs treating. The proportion of surgeons answering the specific HNC questions correctly was slightly lower than in a previous study with head and neck surgeons (Malloy et al., 2013), but knowledge was high in both studies.

Supporting previous research about discussing HPV in the context of the HPV vaccination, health professionals in this study with greater knowledge also had the confidence to discuss HPV and were those most willing to do so in the future (Hopkins et al., 2009). Factors with the greatest association with willingness to discuss HPV in the future were confidence, comfort in talking about sexual relationships, knowledge and positive attitudes to discussing HPV. Health professionals reporting personal barriers to discussing HPV were less willing to discuss HPV, had lower knowledge of HPV and reported the need for more information about HPV. The results from this study identify areas which could be targeted to increase health professionals' confidence to discuss HPV and also their willingness to do so. To increase health professionals' confidence in discussing HPV, improving knowledge and meeting their information needs, as well as addressing their personal barriers for not discussing HPV and their negative attitudes towards discussing HPV, could result in more health professionals discussing HPV with their patients.

A greater proportion of allied health professionals agreed that having a leaflet, regular team updates, regular feedback and attending training would be useful, suggesting that they recognise there is a gap in their knowledge and they are keen to address this. This is supported by previous research with oral health professionals, finding that patient education materials increase comfort levels during patient interaction (Daley et al., 2011). Previous research with oral health professionals has shown great enthusiasm for continued education (Jaber et al., 2012; Malloy et al., 2013; Maybury et al., 2012). Educational materials could be used in future interactions which may help increase knowledge and comfort levels about having these conversations with patients. Didactic approaches such as information booklets, videos and interactive lectures have been found to be effective at increasing knowledge in dentists (Hertrampf et al., 2010). These findings demonstrate that it is not only oral health professionals who are enthusiastic to continue their education, but medical health professionals, especially allied health professionals, are also keen to address gaps in their knowledge.

Some factors demonstrated gender differences between health professionals, where females were less confident, more strongly agreed with the methods to facilitate discussing HPV, had more positive attitudes to discussing HPV and had more information needs than males. As some health professions are more likely to be female-orientated professions and some male,

this could affect the differences in results between the health professional groups. For example, speech and language therapists are more likely to be female than male (Boyd & Hewlett, 2001), therefore the results reflecting gender differences could explain why speech and language therapists exhibit these differences in comparison to some of the more male-oriented professions such as the surgeons.

There are several models of behaviour change that could be useful when thinking about health professionals discussing HPV with their patients, e.g. the Information-Motivation-Behaviour (IMB) model or Capability Opportunity Motivation-Behaviour (COM-B) model. The COM-B model is particularly useful because it can be applied to a broad range of behaviours. Although this model was not used to design the survey, due to the survey being developed based on the results of the qualitative interview study (study 3) and other relevant surveys, the results from this study appear to fit the components of the COM-B model (Michie et al., 2011). As previously discussed in section 3.4.3.1, this model asserts that capability, opportunity and motivation all interact to result in a behaviour, which then impacts upon the three components. In this context the model may help understanding of the skills health professionals need to discuss HPV with a patient (Figure 7.2) and identify which components and which health professional groups could be targeted for future intervention and training.

Assessing the results from this study against the components of the COM-B model show that surgeons and oncologists have the capability, motivation and opportunity to discuss HPV, and that they are discussing HPV. Speech and language therapists and other allied health professionals who do not hold all the components of the COM-B model, are not discussing HPV.

The first component of the COM-B model is capability. Knowledge was shown to be the highest in surgeons and oncologists, and lowest in speech and language therapists and the 'other' group of health professionals. The questions assessing capability demonstrated surgeons and oncologists to have a greater confidence about discussing HPV than the other health professional groups. Knowledge was also found to be associated with confidence in discussing HPV, with previous research in dentists finding associations between level of confidence and the performance of oral examinations or providing advice to patients about risk habits (Saleh et al., 2014).

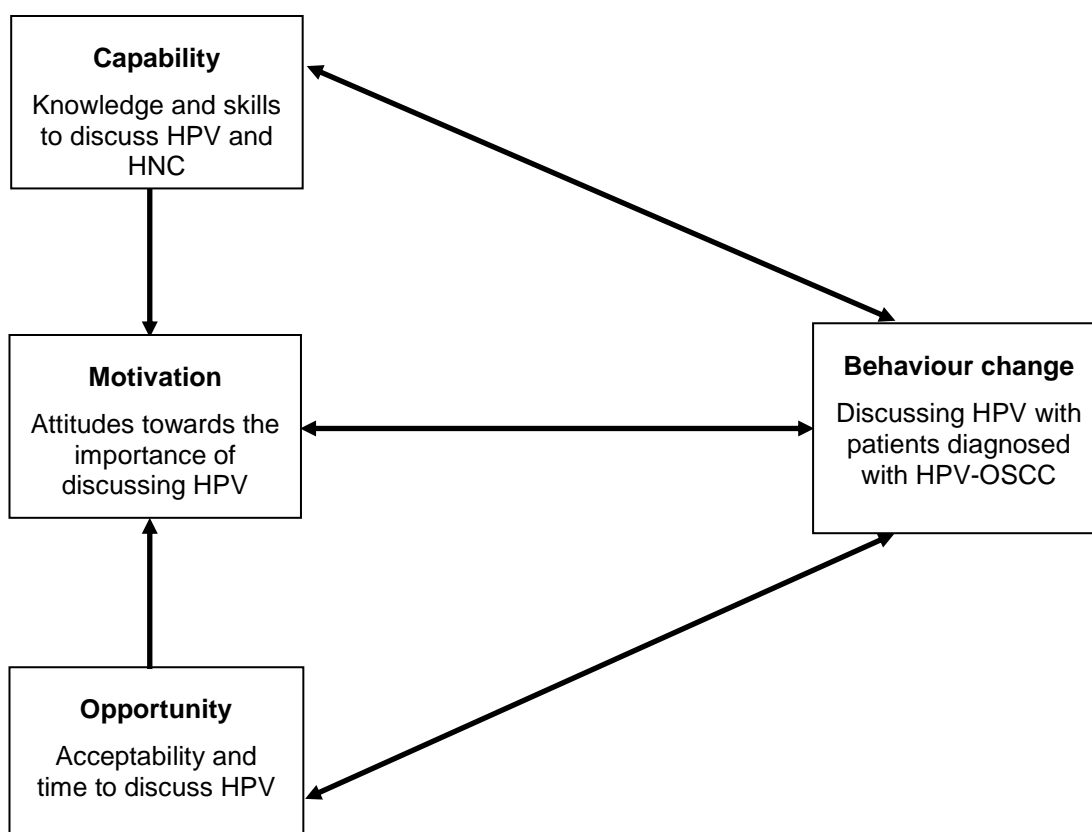


Figure 7.2: The COM-B model in the context of these results

The second component is motivation. The questions in the survey that assessed attitudes to discussing HPV (motivation), showed speech and language therapists and health professionals in the 'other' group reported more personal barriers to discussing HPV such as talking about HPV being embarrassing, and these groups were less willing to discuss HPV. Specialist nurses were the most comfortable talking about sexual health with patients and feel comfortable talking about their patients' sexual relationships.

The third component is opportunity. Greater proportions of oncologists, surgeons and specialist nurses than allied health professionals in this sample had told all or most of their patients their cancer was caused by HPV, had discussed HPV in detail with those patients, and were more willing to discuss HPV in the future. These health professionals are ideally situated to have this discussion with patients as they are likely to see patients more frequently than allied health professionals. As there was still a proportion of allied health professionals who had discussed HPV in detail with these patients, this demonstrates that it is possible for questions to come up at any point during patients' diagnosis, treatment and aftercare and has been found previously (Catt, Fallowfield, Jenkins, Langridge, & Cox, 2005). It is therefore important that all health

professionals dealing with these patients feel informed enough, have the necessary skills, are motivated enough, and have the opportunity to have these discussions with patients. Further training could be targeted at increasing these three components in these health professional groups, to help facilitate the discussions of HPV with patients.

Reasons suggested in chapter 6 for not disclosing HPV as the cause of a patient's cancer support those found in previous research of HPV having no clinical relevance and there being a lack of available prevention and treatment for HPV (Turbitt, Wiest, Halliday, Amor, & Metcalfe, 2014). The Theoretical Domains Framework (TDF) (Michie et al., 2005) has been used previously with regards to health professionals discussing HPV in the cervical cancer context as a basis for developing a theory-based intervention to support primary care practitioners (McSherry et al., 2012). The TDF was developed to synthesise the key constructs used in relevant behaviour change theories and can be used to identify what behaviours need to change with the aim of developing behaviour change interventions. The TDF would be a useful framework to use in future research designed to identify which HPV-related clinical behaviours need to be targeted and to determine what influences these behaviours, to develop an intervention to support HNC health professionals in their discussions about HPV with patients.

7.5 Strengths and limitations

As the factors all had high reliability, the items used in this survey could be replicated in other studies. The range and sufficiently powered large sample of health professionals completing the survey helped in the understanding of different health professionals' positive and negative attitudes for discussing HPV with their patients. The results from this survey support those found in chapter 6 and give more information about specific areas that could be targeted with health professionals working with HNC patients. Due to the nature of the delivery of how the survey was sent to participants, it was not possible to calculate a response rate and therefore it is difficult to assess the representativeness of the responses. Further research would also be needed to determine whether these results extend to other countries, beyond the UK and Ireland. As some of the participants completed the survey at study days, it is possible that some of them completed it following the talks given that day and this could have influenced their responses. Participants were encouraged to complete these at the beginning of the day, before talks commenced. The 'other' professional group contained a mix of health professionals and it

may have been the case that experiences and attitudes differed within the group, but each profession within this group was too small to be able to conduct any meaningful analysis.

PCA as a method of factor analysis has some limitations and the results can be subjective. For example, in this study one of the factors included only two items. A number of arbitrary rules are followed in PCA and there are a number of stages where I had to use my own discretion in the interpretation of factors, in the decision of how many factors to retain and which items load onto which factors. As I did this in collaboration with my supervisors, this should have helped validate my interpretations.

The study was cross-sectional and therefore causation cannot be determined. The items included in the survey were developed from the findings of chapter 6 and from previous literature and so were not validated. Many of the constructs were measured using only one item, such as willingness to discuss HPV in the future. Although some of the questions assessing participants' knowledge were from a validated scale, not all of the questions were taken from validated scales and the internal reliability was found to be questionable and so the results should be interpreted cautiously. Future work should look at validating a measure assessing knowledge of HPV-related HNC.

7.6 Conclusion

This study shows that knowledge, attitudes and beliefs about HPV-related HNC, vary across health professionals, with surgeons, oncologists and specialist nurses having more experiences discussing HPV-related HNC with their patients. These results suggest that knowledge is an important component to discussing HPV and could be targeted in future training with health professionals to increase their confidence in discussing HPV. The COM-B model could be a useful model on which to base future training and interventions to equip all health professionals with the vital components to be able to discuss HPV-related HNC with their patients. Chapters 6 and 7 have provided insight into the impact that the emergence of HPV-OSCC has had on health professionals' clinical practice and their experience of discussing HPV. Health professionals have their own attitudes about discussing HPV and beliefs about what patients want to know and so it is important to explore directly with HPV-OSCC patients what they want to know, as well as their partners who are also shown to be significantly affected.

CHAPTER 8. A QUALITATIVE INTERVIEW STUDY WITH PATIENTS AND THEIR PARTNERS (STUDY 5)

8.1 Introduction

As the previous chapters have presented, the potential for psychosocial distress in patients with HPV-oro-pharyngeal squamous cell carcinoma (HPV-OSCC) is high. This is due to the diagnosis of cancer itself and the potential of disfigurement and dysfunction after treatment. In addition, a diagnosis of cancer caused by HPV, a sexually transmitted infection, may also contribute. Not only does this impart a great burden on the patient, but also on the partner of the patient, who may inevitably become a carer for their partner. Partners are usually involved from the beginning, as they may be the first person the patient discloses their illness to and the rates of psychological distress in partners of HNC patients have been shown to be higher than any other type of cancer (Manne & Badr, 2010). Summarised in chapter 2 is previous research with the partners or carers of HNC patients which has shown them to have their own informational needs alongside their fears and concerns. As chapter 6 presented, sexual relationships with partners may also be affected due to the sexual transmission of HPV.

As patients diagnosed with HPV-OSCC are typically younger, they may also face greater psychosocial challenges associated with long-term survivorship following treatment. HPV-OSCC patients will be required to manage family life, potentially with young children, while managing the challenges associated with the diagnosis and treatment of their cancer (Gold, 2012). As treatment for HNC has been shown to be associated with significant dysfunction and disfigurement, HPV-OSCC patients may need to manage these consequences of treatment long into survivorship. Findings from chapter 6 suggested that these patients also seek expedited rehabilitation for their lives to return to normal as quickly as possible.

To date, there has been little research examining the impact of a HPV-OSCC diagnosis on patients and none of these have examined the impact on the patients' partners. The increasing incidence of HPV-OSCC worldwide highlights the need for research exploring the impact of the diagnosis on patients and their partners to enable us to understand the implications of the diagnosis, and possibly help alleviate any anxiety by developing an information and support

package for patients and their partners. There is a need for clear and consistent health messages aimed at diminishing stigma, fear and self-blame (Daley et al., 2010). This interview study (study 5) aimed to explore the psychosocial impact of being diagnosed with HPV-OSCC on both the patient and the patient's partner. This study contributes to the seventh and eighth research questions:

- 7) What is the psychosocial impact on patients being diagnosed with HPV-OSCC?
- 8) What is the psychosocial impact on partners of patients who have been diagnosed with HPV-OSCC?

8.2 Establishing a Participatory Advisory Group

Prior to beginning recruitment for study 5, I established a Participatory Advisory Group (PAG). The involvement of patients and the public in research and development is increasingly being recognised as important, with the Department of Health supporting the role of the public in the processes of health research (Department of Health, 1999). Patients and the public can provide different perspectives to researchers about what research is important and the best strategies for achieving the research outcomes. The National Health Service (NHS) has a clear policy directive to involve patients and the public in research and development (Department of Health, 1999) and it is encouraged to support ethical applications for research with NHS patients. Due to the planned involvement of NHS patients in some of my research, I decided to establish an advisory group to ensure high quality acceptable and clinically relevant research.

This PAG was established prior to designing study 5 with the intention of members being involved in testing and commenting on the acceptability of research materials and procedures for this study and future research studies. Recruitment to the PAG was approved by the UCL Research Ethics Committee, reference 4577/002 (Appendix 8.1).

8.2.1 Recruitment of PAG

An advert was placed on The Throat Cancer Foundation website in August 2014 (Appendix 8.2) to recruit HNC patients 'to help us try out research materials for studies exploring experiences of being diagnosed with head and neck cancer'. Responses to the advert were received until August 2015. Potential participants were advised that they could be asked to take part in

practice interviews or focus groups, comment on questionnaires which could be used in larger studies, and/or advise on future research studies (Appendix 8.3). Participants were eligible if they had been diagnosed with HNC and were able to communicate in English. Interested participants were asked to complete a short online questionnaire and consent form (Appendices 8.4 and 8.5). The online screening questionnaire helped determine their eligibility for different pilot studies and provided information about what types of pilot studies they were happy to be involved in. The participants gave their contact details at the end of the questionnaire so that I was able to contact them regarding involvement in pilot studies or another PAG activity, and this also indicated consent.

8.2.2 Characteristics of the PAG

Nineteen patients completed the screening questionnaire. Three patients did not include their contact details and had to be removed from the PAG list. Patients were diagnosed between October 1999 and December 2014. In terms of treatment, one patient received surgery alone, nine patients had surgery combined with chemoradiation, one patient had surgery combined with radiation, one patient received only radiation and four patients received only chemoradiation. There was an even split of male and female patients, most were married, with a mix of employment status, most being either employed full-time, disabled or too ill to work or retired. Six of the 16 patients knew that their tumour was tested and confirmed as HPV-positive. Characteristics of the PAG are shown in Table 8.1.

Table 8.1: Characteristics of the PAG

	Patient characteristics (n=16)
Age at diagnosis [median (range)]	53 (34-67)
Sex [n]	
Male	8
Female	8
Marital Status [n]	
Married/Civil Partner	9
Long term partner but not married	3
Widowed	1
Separated	1
Single	2
Employment status [n]	
Employed full-time	4
Employed part-time	1
Retired	5
Disabled or too ill to work	4
Carer	1
Full-time homemaker	1
Primary cancer [n]	
Oropharynx	1
Larynx	2
Base of tongue	5
Throat	2
Tonsil	6
Smoking status [n]	
Current	2
Former	9
Never	5
Knew their cancer was HPV-positive [n]	6

8.3 Methods: Main study

8.3.1 Participants

Eligible participants were identified by medical staff from patient's medical records at Aintree University Hospital, Liverpool and Brighton and Sussex University Hospital, Brighton. Patients were also going to be recruited through University College London Hospital, but due to organisational difficulties, no patients were recruited from this site. Patients were eligible if: they tested positive for HPV; were at least one year post diagnosis of HPV-OSCC; they could communicate in English both orally and through writing; and they were able to give informed consent. Partners were eligible if: their partner (the patient) met the patient inclusion criteria; they were also able to communicate in English both orally and through writing; and they were able to give informed consent. Eligibility was established using the patients' medical records by members of staff at Aintree University Hospital and Brighton and Sussex University Hospital. Ethical approval was granted by South East London NHS Research Ethics Committee (Reference: 15/LO/0803) (Appendix 8.6).

8.3.2 Materials

The interviews followed a topic guide that I developed using the existing literature on patient experiences and previous work on HPV and cervical cancer. The interviews began with an open question about the participant's experience of being diagnosed or of their partner being diagnosed. The rest of the interview was prompted by responses to this question, but included questions about symptoms, diagnosis, any psychosocial impact and information needs (Appendices 8.7 and 8.8).

Piloting

PAG members were recruited to the pilot study on the basis of their responses to the online questionnaire. If participants had indicated they knew that their tumour had been tested for HPV and that this was positive, they were contacted about taking part in pilot interviewing to test the interview topic guide for the main study. Three patients were contacted and two responded to say they were interested in taking part. These patients also indicated that they had partners and were asked if they would be happy if they also took part. Consent was obtained from the

partner. One partner took part and the other patient's partner was not available at the time of the interview. As all participants were happy with the questions asked in the interview and did not think any changes needed to be made, the interviews of these three participants were included in the larger study.

8.3.3 Procedure

Sixty eligible participants at Aintree University Hospital and 29 eligible participants at Brighton and Sussex University Hospital were invited to take part in the study through an information pack sent in the post. Similar protocols were run at each NHS site (Figure 8.1). The information pack contained an invitation letter addressed from the hospital, an information sheet, a short questionnaire and a consent form with a Freepost envelope enclosed for the return of the questionnaire, consent form and contact details form (Appendices 8.9, 8.10, 8.11, 8.12). If patients had not returned their questionnaire and consent form after three weeks, a second invitation letter (Appendix 8.13) with the information pack was sent out. The participants were aware that I was a researcher studying for a PhD and was interested in their experiences of being diagnosed with HPV-OSCC or of their partner being diagnosed with HPV-OSCC, which was explained on the study information sheets (Appendices 8.10, 8.14) provided to them prior to them consenting to take part.

If patients had indicated on their questionnaire they knew that their tumour had been tested for HPV and that this was positive, primarily it was those patients whom I contacted about taking part. Once the patient had returned their contact details form, I contacted them to ask if they had any questions about the study and then if they were happy to take part, I arranged an interview date with them. Patients indicated on their consent form whether they were willing for their partner to be contacted to take part in the study. When I contacted the patient, I asked those who had indicated they would be happy for their partners to be contacted whether they were happy for me to send their partner an information pack in the post (Appendix 8.9, 8.14, 8.15, 8.16). Patients were still able to take part regardless of whether they had a partner or not, or if their partner was not taking part. I contacted partners who had been sent an information pack in the post after giving them time to read it and if they were happy to take part, arranged an interview with them for the same time as the patient. Consent from partners was collected at the time of the interview. My relationship with the participants prior to the interviews involved

contacting them to arrange the interviews and confirming the interviews closer to the interview date.

I carried out in-depth interviews with the patients and, where possible, their partners. Patients and their partners were interviewed separately. Interviews with patients took place face-to-face at their home (n=18) or over the telephone (n=2) and lasted 35-84 minutes. Interviews with partners took place face-to-face at their home (n=11) or over the telephone (n=1) and lasted 26-55 minutes. One interview that was arranged had to be cancelled for personal reasons of the participant. I conducted and digitally recorded all the interviews. They were transcribed verbatim by an external transcription company as soon as they have been conducted. Emerging themes from the interview transcripts were noted simultaneously with carrying out the interviews. Once I was satisfied that no new themes had emerged from three consecutive interviews, I took this to indicate that saturation had been achieved. Data collection ceased at this point (Francis et al., 2010). For the same reasons as previously explained in chapter 6, transcripts were not returned to the participants for comment or correction. Information about patients' diagnosis were obtained from their medical records.

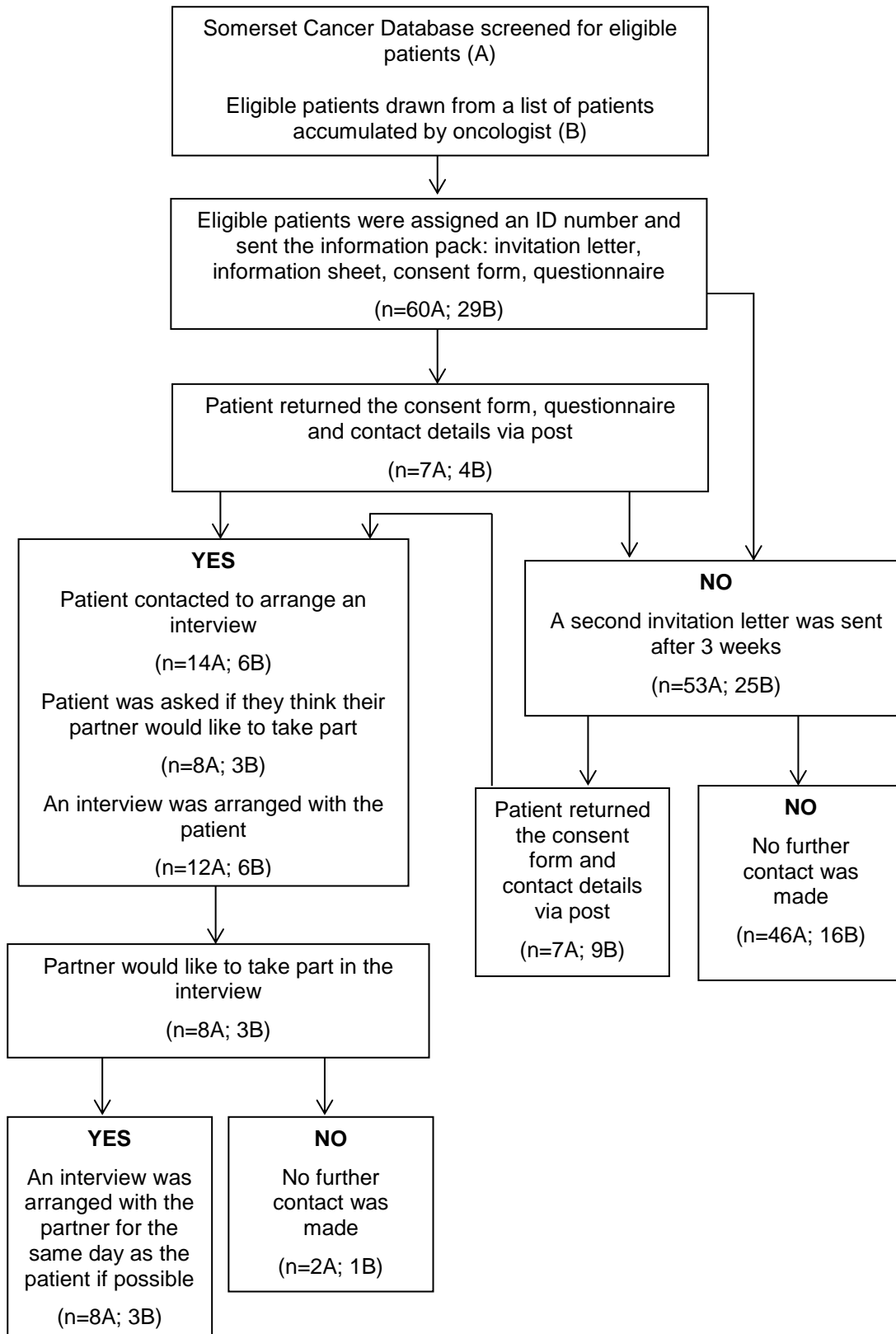


Figure 8.1: Recruitment at Aintree Hospital (A) and Brighton and Sussex Hospital (B)

8.3.4 Analysis

The audio recordings of the interviews were sent to a transcription company to transcribe. On their return, I uploaded the transcripts to NVivo 11 (QSR, 2015). Data was coded into common themes in NVivo. Dr Jo Waller and Dr Alice Forster read 10% of the transcripts each (n=3) and developed codes independently. All coding was then discussed and any disagreements were resolved before I coded all of the transcripts. Once all of the data had been coded in NVivo, the framework matrix included all participants in rows and themes in columns, with the cells showing summarised data. This enabled me to view the sections coded for each participant and view which themes were most prevalent. This method is known as Framework Analysis (Ritchie & Spencer, 1994) and was chosen because it aims to generate themes and make comparisons both within and between cases and is not aligned with a particular theoretical approach (Gale et al., 2013). Patients and partners were all treated as separate participants as I was interested in each participant's individual experience. Dr Laura Marlow read a further 10% of the transcripts and checked her agreement against the coding framework.

This analysis of data allowed me to gain an understanding of the experiences and psychosocial impact of a diagnosis of HPV-OSCC on both the patient and their partner.

8.4 Results

Out of 89 patients sent an information pack, 27 sent their consent forms back, giving a response rate of 30% (Figure 8.1). The characteristics of the non-responders are not available as I had no access to any of their data due to them being approached by the clinical teams at each NHS site. I interviewed 18 patients and 11 partners across two NHS sites between September and November 2015. Interviews with two patients and one partner were included from the pilot study and were interviewed in September and October 2014. Patients were diagnosed between June 2011 and September 2014, with an average time since diagnosis being 22.85 months (range 12-53 months). All were diagnosed with a primary tumour in either their tonsil (n=14) or base of tongue (n=5) and all except one at the most advanced stages of IV A to C. In terms of treatment, one patient received surgery alone, five patients had surgery combined with chemoradiation, five patients had surgery combined with radiation and eight patients received only radiation. The medical records for one patient were not obtainable. The majority of the

patients were male, white British, married or cohabiting, with a mix of employment status, most being either employed full-time or retired. Characteristics of the patients are shown in Table 8.2 and partners in Table 8.3.

Table 8.2: Patient characteristics

Patient characteristics (n=20)	
Age at diagnosis [median (range)]	57 (40-82)
Age at interview [median (range)]	59 (41-83)
Sex [n]	
Male	14
Female	6
Ethnicity [n]	
White British	19
Other	1
Marital Status [n]	
Married/Cohabiting	14
Widowed	2
Divorced	2
Separated	1
Single	1
Employment status [n]	
Employed full-time	7
Employed part-time	2
Unemployed	1
Retired	8
Disabled or too ill to work	2
Knew their cancer was HPV-positive [n]	12

Table 8.3: Partner characteristics

Partner characteristics (n=12)	
Age [median (range)]	59.5 (45-74)
Sex [n]	
Male	2
Female	10
Ethnicity [n]	
White British	12
Marital Status [n]	
Married/Civil Partner	12
Employment status [n]	
Employed full-time	1
Employed part-time	5
Retired	5
Disabled or too ill to work	1
Knew partner's HPV status	5

A large quantity of data emerged from the interviews and the entire framework which includes the themes generated from all participant interviews is presented in Figure 8.2. Themes interpreted from the data which are not referred to in this chapter relate to experiences with the healthcare system, person factors (e.g. lifestyle, comorbidities) and other cancer-related impacts. Experiences with the healthcare system reflected participants' direct experiences with healthcare professionals and their experiences of symptoms, diagnosis and treatment for which participants gave much factual detail. Person factors reflected other individual aspects which did not impact upon perceptions of HPV-OSCC. The final theme reflected other ways in which the diagnosis had an impact, which were not psychological. These themes do not relate directly to the research question and therefore are not discussed here.

The data were examined to understand the psychosocial impact of being diagnosed with HPV-OSCC, looking at individual experiences for both the patient and their partner, and to explore how this varied between participants. Initial reactions to being diagnosed with cancer included shock, panic, being destined to the diagnosis, thinking they were going to die, feeling vulnerable and frightened. A small number of patients said that the diagnosis was not a shock and a few of them felt like it was not happening to them.

For this thesis I have focused on the themes and subthemes that related to the aim of the study which was to explore the psychosocial impact of being diagnosed with HPV-OSCC for both the patient and the patient's partner. Therefore this chapter focuses on: beliefs about the cause of their cancer, disclosure of results to others, being diagnosed with HPV, prognosis, questions and information about HPV and their cancer, the psychosocial impact and impact on others.

Two case studies are included to provide context of two patients who were aware of being HPV-positive and demonstrate how the context is relevant to the impact of being diagnosed with HPV-OSCC (Yin, 2003). For the themes which focus on HPV, the data presented here focuses on the 12 patients and their partners who knew they were HPV-positive. Where quotes are used, participants are described using their gender (M/F), unique identifying number and age. Partners are distinguished with the use of a 'P' at the end of the unique identifying number.

Included themes	Not included themes
Beliefs about the cause of their cancer	<i>Experiences in the healthcare system</i>
<ol style="list-style-type: none"> 1 HPV or virus 2 Does not know the cause of their cancer 3 The cause of their cancer did not matter 	Health professionals and hospital
Disclosure to others	<ol style="list-style-type: none"> 1 Attitudes 2 Experiences with health professionals 3 Trouble with services 4 Positive experience
<ol style="list-style-type: none"> 1 Disclosure of the cancer <ol style="list-style-type: none"> i. Keeping others informed 2 Disclosing HPV as a cause to others 	Check ups
Being diagnosed with HPV	Symptoms and diagnosis
<ol style="list-style-type: none"> 1 Reactions to being diagnosed with HPV 2 When and how to be told about HPV 3 HPV vaccination 	<ol style="list-style-type: none"> 1 Symptoms and attributions 2 Diagnosis 3 Help-seeking 4 Misdiagnosis 5 Reaction to diagnosis 6 Reaction of others
Prognosis of HPV-related cancers	Timelines
Questions and information about their cancer	<ol style="list-style-type: none"> 1 Time to diagnosis 2 Move quickly 3 Timeline to normality
<ol style="list-style-type: none"> 1 Information given about diagnosis and treatment 2 Understanding of HPV <ol style="list-style-type: none"> i. Searching for information about HPV 3 Need for more information 4 No need for more information 	Treatment and medication
Psychosocial impact of the diagnosis and treatment	<ol style="list-style-type: none"> 1 Preparing for treatment 2 Involvement in decisions 3 Radiotherapy and chemotherapy <ol style="list-style-type: none"> i. During treatment 4 Feeding tube 5 Medication 6 Finishing treatment
<ol style="list-style-type: none"> 1 Responses to the diagnosis 2 Partners: Feelings about their partners cancer 3 Partners: Taking control 4 Social 5 Work 6 A different perspective on life 7 Feelings about the future 	Waiting for something to happen
Impact on others	<i>Person factors</i>
<ol style="list-style-type: none"> 1 Impact on family members 2 Effect on partner 	Comorbidities
	Lifestyle
	Other experiences with cancer
	Other stresses
	Awareness and beliefs about cancer
	<i>Other cancer-related impact</i>
	Impact
	<ol style="list-style-type: none"> 1 Effects of treatment 2 Financial 3 Physical 4 Practical
	Recovery
	Support
	<ol style="list-style-type: none"> 1 Support from family and friends 2 Support from health professionals 3 Support from hospital and organisations 4 Support of partner 5 Support available 6 Practical support 7 No external support 8 Support groups

Figure 8.2: Framework with the themes focused on in this chapter in the left-hand column

8.4.1 Beliefs about the cause of their cancer

This theme is directly linked to the research question and distinguishes between patients who knew about HPV and those that did not. It covers the cause of patients' cancer, whether it was talked about, whether patients knew or wanted to know the cause, and whether knowing the cause mattered.

HPV or virus

All patients discussed the cause of their cancer; almost a third of patients brought up the cause and the other cases were prompted by the researcher. Some patients were told that their cancer was caused by HPV or 'by a virus':

'I was probably midway through my hospital stay when the doctor mentioned it was because of HPV, which opened up even more questions to me because I didn't even know that it can cause that'. (F02, 41 years)

Patients did not always find out about HPV being the cause of their cancer from their doctor. A couple of patients found out after being approached by a member of a clinical trials team asking about them taking part in research:

'I only found out because... they didn't... nobody told me. Erm, he was doing, erm, err, you know, kind of like a survey looking into, erm, things, and will I be interested afterwards in, you know, taking part in that because my diagnosis was HPV? And, erm, I had no idea what he was talking about ... So, yeah, that's how I found out'. (F58, 61 years)

HPV was not always accepted as the cause of cancer, with one partner describing a conversation with her friend who was a nurse and dismissed HPV as the cause of her partner's cancer:

'I sort of Googled it and I know [name of friend] made the joke about, uhm, it - it could be done - it - it's something that's often caused by oral sex, or something or other. Uhm, but it - that's a load of nonsense in his case, or something or other. So, other than that, no, absolutely no idea of the how or why or anything'. (F06P, 64 years)

Some patients were still not being told about HPV as the cause of their cancer despite having been tested for it. A patient whose brother-in-law had also been diagnosed with HPV-OSCC specifically asked his doctor if he had HPV and was told he had 'been unlucky' and that they had not found HPV. Another patient was angry that she had not been asked if she wanted a test for HPV:

'Well, it doesn't make me feel any better, because even... you know, still even then, if I have been tested for something, nobody's given me any results or, you know, or even told me I've been tested for it. Um. Don't get me wrong, I wouldn't refuse, but by the same token I think I should have been asked, or been told, 'We're going to test, and..' ... You think it's just general'. (F20, 58 years)

Does not know the cause of their cancer

A number of patients had not been told what the cause of their cancer was and so in searching for a causal attribution, some attributed it to smoking, related it to work or genetics.

'You know, dusty, dirty atmospheres: am I breathing that in? Because me first one was... me primary was me tonsil. Erm, chemicals, nasty stuff. And back in the 70s and 80s when I was working, there was nothing... PPE and all that, you just got on with it. You know, you didn't have all the stuff you have on now. I mean, I've worked with asbestos'. (M59, 56 years)

Another patient described it as a 'self-inflicted illness' and believed 'it's pointless doing something [smoking] for pleasure which is gonna ruin your health' (M50, 83 years).

There were some patients who had not been told the cause of their cancer and expressed the view that they wanted to know.

'Like I say, I would have loved, "Yeah, that's what's caused it." But to this day, I don't know. I don't know what it is'. (M59, 56 years)

The cause of their cancer did not matter

Nearly half of the patients said it did not matter what had caused their cancer, the most important thing was that they had got rid of it. The cause was also seen as something that could not be changed, 'I can't go back and say I'll not do that' (F55, 66 years) and that it did not affect the treatment. This partner expressed her relief that her husband's cancer was now gone:

'I don't care how it was caused. It was just that it's gone, we hope, you know. We know we don't get an all-clear for five years but, erm, fingers crossed, you know'. (F06P, 64 years)

One patient thought that as HPV had not been discussed, that means 'it can't be much of a problem'. One patient believed nobody was really bothered how they had got their cancer:

'Umm, I know the HPV's really interesting and different and people need to know about your lifestyles, and stuff, to try and stop other people getting it, but, erm, I think the people who do get it don't give a damn about the HPV, or most of them'. (F58, 61 years)

8.4.2 Disclosure to others

Disclosure of the cancer

Participants took different approaches to telling other people that they had been diagnosed with cancer. Some participants did not want to tell anyone their diagnosis, wanting to keep it to themselves and being aware that this was something with an immediate impact on others. Disclosing their diagnosis of cancer was something that patients did not look forward to doing, or sometimes even want to do.

‘[Name of patient] didn’t want to tell anyone. I don’t know why. I don’t know... I mean he did eventually, obviously. And he didn’t really want to talk about it ... I mean, him and his brother [name of patient’s brother] were quite close, and I couldn’t understand why he wouldn’t want to tell his brother’. (F56P, 59 years)

Reasons given for not telling people were around not feeling comfortable, waiting for the prognosis before telling people and not wanting to burden other people. This often delayed the disclosure of their cancer diagnosis to other people, but the disclosure would happen eventually. One couple decided not to tell anybody until after the operation.

‘Uhm, possibly cause it was Christmas-ish it helped, because we have a fabulous social life, uhm, and we decided not to tell anybody, apart from [name of friend] and her now husband [name of friend’s husband]. We didn’t tell anybody else at all. We kept it to ourselves’. (F06P, 64 years)

Some participants minimised what was happening when they told people about their cancer diagnosis and wanted to be able to keep them calm and reassure them everything would be okay. One patient waited until he saw people to tell them, as he did not want to tell people over the phone. Another patient had found out his diagnosis on the day of a friend’s birthday and his partner explained that they ‘didn’t want to ruin his birthday’ (F12P, 51 years).

Keeping others informed

Another aspect relevant to participants was the need to keep everyone informed, which was described as ‘emotionally draining’ (F59P, 49 years). Participants recognised the importance of both being kept informed and keeping the family informed about how the patient was. One couple, when referring to their children, said they ‘kept them regularly updated every time I went to clinics and things’ (M31, 61 years), but think ‘it’s probably still in the back of their minds, if you know what I mean’ (F31P, 56 years). Being honest was seen as important. Some partners

found keeping people up-to-date was tiring, having to answer people's texts and phone calls.

One partner adopted a strategy to keep everyone updated at once:

'I didn't want to leave it off the hook because people would think, I'm in and not answering it or I'm, there's something wrong, so I told everybody when they rang me, I said, don't call me again, I've got your email address, I'll send out an email'. (M61P, 74 years)

One of the partners recognised that perhaps sometimes she and her husband forgot to keep people updated, 'because we were so cocooned in together in what was going on' (F47P, 45 years).

Disclosing HPV as the cause to others

A couple of patients gave examples of why they thought others did not ask them about the cause of their cancer, believing that 'the cancer word's enough for most people' (F58, 61 years) and 'they think well you get cancer and you just get it, it's one of those things that happens' (M31, 61 years). Some patients who knew that HPV was the cause, felt uncomfortable talking about it with others: 'It's not a conversation you really want to have with your daughter' (F20, 58 years). One patient described telling people 'It's viral, in my throat, very treatable, a type of skin cancer, it comes from HPV' and that 'you don't go around broadcasting that something's sexually transmitted' (M9, 49 years).

One patient said she found it easier to tell other people than her partner and that she had told others about HPV before she had told her partner:

'I don't think I told [name of partner], my partner, what it was... When they told me it was because of HPV I don't think I told him for ages ... I think it was easier to tell other people why as opposed to him. And I don't really know why on that one. I don't know'. (F02, 41 years)

One partner described how everyone assumes HNC is caused by smoking and how people reacted when she and her partner told them about HPV and that most friends said they looked it up on the internet after they had explained:

'They were quite sort of, ooh. It's a bit like anything you've never heard of before, you think, gosh, now that's an eye opener, didn't know that could happen or exist'. (F10P, 60 years)

Reluctance to discuss HPV as a cause of their cancer with others was evident, not fully disclosing their diagnosis to others and viewing it as a 'medical thing' so only felt comfortable

talking about HPV with medical people. One patient explained how she feels ‘stigma attached to it [HPV]’, due to the negative reactions of other people and how this has prevented her from disclosing where her cancer had come from. This patient did then disclose that compared to before, she felt more comfortable talking about HPV after her consultant had told her:

‘This is the most contagious virus in the world, er, 95% of people manage to disperse it through their immune system, 5% don’t and unfortunately, 5% of that 5% it turns to cancer and you’re unlucky’. (F13, 42 years)

Some participants also brought up Michael Douglas and viewed what he had said as ‘not helpful’ and there was a ‘sensationalist aspect’ surrounding the sexually transmitted nature of HPV. One partner described how she was happy telling people that her partner’s cancer was caused by HPV before Michael Douglas said that ‘it’s caused by oral sex’.

‘Well, to start with probably I was quite open telling people that [name of patient]’s cancer was caused by HPV but, after that, a bit more reluctant to discuss it. Which is a shame, because I think that more people need to be aware of this, but it’s difficult’. (F01P, 62 years)

8.4.3 Being diagnosed with HPV

This theme describes reactions to being diagnosed with HPV, preferences for being told about HPV and about the HPV vaccination.

Reactions to being diagnosed with HPV

Patients’ reactions to news of their cancer being caused by HPV were embarrassment, confusion, surprise, disappointment, shock and feeling unlucky. One patient described how she still has ‘got a little bit of an issue still with it’ and how her husband had ‘said something that made me feel really dirty’ (F13, 42 years).

‘Yeah, pretty disappointed really, um, and, you know, slightly, I don’t know slightly concerned that I’d got it, you know, either from my wife or from a previous partner’. (M9, 49 years)

One patient explained how she was embarrassed about the HPV aspect of her cancer, but how it feels less relevant now, with the cancer being most important, not the cause:

‘I think that was the worst... I was embarrassed at first, but then, yes, after a little while you just... again, whichever way I got throat cancer, I got throat cancer. So now I think, two years on, or nearly two years on, I think it’s less relevant’. (F02, 41 years)

Transmission of HPV to their partner was a concern for some patients and one of the partners decided to get tested privately for HPV.

‘And I’m thinking, I don’t want to pass this thing on to my wife, or if she’s got it and I’ve cleared and she passed it back to me, it’s potentially passing it backwards and forwards’. (M01, 59 years)

When and how to be told about HPV

There were mixed opinions from patients about when would be the best time to have been told about HPV as the cause of their cancer. Patients recognised that the initial diagnosis stage might not be the best time, but other participants thought it would have been helpful to know at the beginning, when they were first told about their diagnosis.

‘So yeah, just clear information when you are diagnosed or at the point of... Maybe when you’re diagnosed is an awkward one, because, like I said, that appointment to me went through in a blur. But maybe a doctor somewhere just having a half an hour chat, being able to have half an hour with you to talk through everything when things are a bit clearer in your head. Which, you know, they’re so busy’. (F02, 41 years)

This patient also described how she was told about HPV and how this was not how she believes she should have been told:

‘When I found out I had it because of HPV, it came out... it was like a midnight conversation of the doctor doing his rounds and I was awake so we got chatting. And it wasn’t... at the time and everything, but it was like... how it just came out totally at random. Now, whether it’s because it’s not relevant to how they treat. But, to me, if you are gonna be told something like that, which psychologically becomes very relevant, it would have probably been better to have known in a proper way not just a chat’. (F02, 41 years)

HPV vaccination

The HPV vaccination was brought up by a few participants with children who are boys and will not receive the vaccination, and one couple had got themselves vaccinated against HPV.

‘What, an, angers me is the fact that boys aren’t, don’t have the HPV vaccine, um, because when I was talking to [name of doctor] he said, you know, this, this will be null and void when I’m in my rocking chair, he said, because obviously down to the, to the injections the girls have now, but that clinic was full of men. You know? And it just seems a bit unfair that, in fact I even looked at, um, getting my son immunised, um, privately for that reason’. (F13, 42 years)

8.4.4 Prognosis of HPV-related cancers

Most of the patients given information about their prognosis were told that it was treatable, curable and they could expect to recover completely. The statistics given to patients ranged from 50-85% survival, with research showing higher survival rates for HPV-related diagnoses:

'So I mean, the oncologist told me I had a 60% to 70% chance of survival, erm, unless it was HPV then it was 70% to 80%. So I'd just been given an extra 10% survival. That's very nice!' (M01, 59 years)

Patients were reassured by the better prognosis given to HPV-related diagnoses and one patient described how he focused on the words 'it's treatable' (M59, 56 years). One patient interpreted 80% as good, but then put the statistics into real life when he saw the radiotherapy masks lined up in the room.

'She [radiographer] said, we've got 42 masks at the moment. And I'll tell you what kicked in then, there's eight of us not going to make it then. That, that's what was in my mind. Whether she, that was just the way I think anyway'. (M12, 53 years)

Finding out the cause was HPV was seen as something positive due to finding information from research studies showing that it is a much more treatable cancer. This partner indicated her relief of finding out this information:

'So once we did find, it took a little while, that he was HPV-positive, and I think all the signs were he was, erm, that we felt a lot better about that'. (F01P, 62 years)

8.4.5 Questions and information about their cancer

This theme relates to discussion around information the patients and their partners were given about their diagnosis and treatment, their understanding of HPV, searching for information about HPV, their need for more information and there being no need for more information.

Information given about diagnosis and treatment

A number of the participants described having been given information in the format of books or leaflets. One patient also reported having been given a CD with pictures and stories of people following surgery who had had mouth cancer, which 'frightened the pants off me, which I don't think they should have done!' (M01, 59 years). A couple of participants reported on where they kept the information, such as organising them onto a table or into a box file. The information given tended to reflect general information about HNC, on treatment and side effects,

rehabilitation exercises and other health conditions. One patient also described how he was given a leaflet to use as a prompt for any questions he wanted to ask:

‘Yeah. Err, he gave me a leaflet and what he said to me was to write it all down on a piece of paper. He said, “Now, after I’ve saw you, you’ll be coming in to see me again,” and he gave me a fact file on everything’. (M22, 59 years)

Many of the participants described how information about the treatment plan and what they were going to do was explained to them, with the aim of keeping them calm. Some patients were also told about some of the effects they could experience following treatment, such as restricted movement of the neck, tiredness, and possible future thyroid issues. Some patients also mentioned things that happened that they were not told about, such as loss of saliva, how bad they were going to feel after the treatment and potential effects of morphine.

Understanding of HPV

In terms of information participants were given about HPV, this very much varied. Information patients described getting when they were told about HPV included it being discussed in relation to cervical cancer, that ‘the HPV virus is in all of us’, and that ‘it has been written up that it can be from cunnilingus’. Most participants had never heard of HPV before they were diagnosed. Those that were already aware of HPV tended to be women who had heard about it in the context of cervical cancer.

‘Obviously, I heard about HPV but not in this context. Erm, I’d always been for my cervical smears and they’d always been fine’. (F01P, 62 years)

Some of the understanding about HPV that participants came away with from their doctors were that it’s ‘a virus’, ‘it’s sexually transmitted’, it ‘seems to affect anybody’, ‘you could have it for years’, it’s ‘the most contagious virus in the world’, ‘it’s on the increase’ and it’s ‘becoming more and more common in all ages’.

‘He explained then that it was this papilloma virus and I asked if I could get it and he said, you know, it’s in all of us, anyone can but that they didn’t know really what specifically caused it ... it’s in people that are sort of sexually active, um, and that it can, that they’ve realised that there’s a lot more cases ... Um, and that, I know that they said it was quite sort of, it was becoming more and more common in all ages’. (F10P, 60 years)

Questions participants had about HPV included whether HPV is likely to travel around their body, ‘what’s the chance of it coming back’, ‘where has this [HPV] come from’, ‘how’s it taken so

long to come through', have they still got HPV, 'is it only sexually transmitted', how long have they been carrying HPV, what is the prognosis, will the treatment get rid of HPV and are their children more at risk of HPV.

'I mean, I know [name of patient] does an awful lot of swimming, and a few years ago he had a dreadful bout of verrucas, and they spread to his hands. He had a lot of warts and things like that. So I think, well has he got some sort of susceptibility to this sort of thing? Could it have been that we've been passing it between ourselves for years and years? I mean I've actually got some warts on my hands as well that I can't get rid of, which I've had for quite a while. I didn't realise it was a wart until I went the doctor quite recently and had this thing on my hand'. (F01P, 62 years)

One patient was reassured by a friend who works in a hospital, that people's interpretation of HPV being down to oral sex, 'is their naivety'. One patient believed that there were ways, other than oral sex, that HPV could be transmitted.

'I mean surely if you can transmit the virus around, there's going to be other ways of doing it as well, surely? It could be a cut on your hand, it could be a kiss, it could be anything, couldn't it really? You just don't know really. I don't think the authorities do yet either, that's the impression I get'. (M01, 59 years)

Searching for information about HPV

Although the internet was a popular source of information for participants, there was an understanding that this should be done with caution: 'I know you shouldn't, but you look online, don't you?' (F20, 58 years). It was also recognised that the information is not always trustworthy or 'regulated':

'There's no real, kind of, er, evidence to support a lot of the, kind of, things that are said online'. (M9, 49 years)

A few did not want to look for any more information and not on the internet for reasons such as that they did not want to 'panic' or read the wrong information.

'No. I never look on the Internet for anything like that, because I don't think... rightly or wrongly and umm... it's no disrespect to anyone who put it on there, but they don't know like the professionals'. (M22, 59 years)

Some patients looking for more information found information that confirmed what they had been told by their doctor.

'And they [websites] were saying basically the same as, as he did, you know, that, err, there are various ways you can get it, that it can lie sort of within your body for years. Some people, most people get rid of the, the virus within a couple of weeks or a month of, of contracting it, and sort of perhaps 99% of the population have had it at some time

and don't realise, and that there's just some people for some reason it, err, it stays within the body, you know, it doesn't, err, it doesn't disappear like it should do, sort of, in a normal situation. So yes, I had some idea and he sort of just confirmed what I'd, what I'd read'. (M31, 61 years)

The internet was used to look for information on HPV, information about the best treatment options, researching symptoms, causes, information on their doctor, explanations of tests and for further information about their particular cancer. It was recognised that there was not much information out there on the Cancer Research UK website about HPV, but that the Mouth Cancer Foundation had more information.

'And it was him that, and his exact words were, because, when you get home, being told it's HPV, you Google everything, and I Googled it and I broke down, because I just thought, I can't believe what, it, er, it was all over the internet that it was all down to oral sex, etc, etc'. (F13, 42 years)

For those that did further research into HPV, the level of research undertaken also varied. One partner read research papers on HPV from the USA and took away the information that the prognosis is good, and that it affects men in their 40s and 50s 'who are quite healthy' (F01P, 62 years).

'Unless somebody had another type of cancer, it seemed like the chances of recurrence were pretty low after the sort of standard treatment, which was what [name of patient] had had. So I was pretty reassured by that'. (F01P, 62 years)

Some participants expressed concern that the information currently available was not very applicable to them. One patient pointed out how information about HPV seems to be 'centred on teenagers' and being 'either aimed at young people not contracting HPV or old people not getting cancer through HPV'. This particular patient was a female, in her 40's, so she felt like the information available about throat cancer was aimed at 'that sort of age group – 60 plus. And you are like, well, that's not me' (F02, 41 years).

Need for more information

In terms of getting more information from health professionals, some partners felt like they could ask anything, with one partner feeling guilty because she was 'asking all the questions and it's not me that's affected' (F56P, 59 years). More specifically participants would have liked to have known more about the effects of the treatment, follow-up treatment plan, radiation burns, and ideas about food for the patient. Questions also came up with regards to what the treatment was going to involve and feeding tubes, as well as whether it was curable and what the main

effects of the treatment would be. Some patients also acknowledged that they were not sure what questions to ask.

One of the partner's also recognised the challenges with giving information in that 'everybody's different'.

'I've been, I've been thinking about that, the thing is everybody's different, and if you start, start saying, you know, your hair's gonna come out, you're gonna lose your voice and things like that, you're, you're waiting for it to happen'. (M61P, 74 years)

It was acknowledged that there was a need for more research to be done in the area and that there will be more known about HPV-OSCC in a few years' time, and that further research may lead to different and 'milder treatment' for HPV cancer, with this one partner hoping this would mean people 'wouldn't have had to go through the dramatic treatment he did have to go through' (F01P, 62 years).

'I think it just needs more research doing, but I think, at the moment, we're just happy that [name of patient]'s going to get over this thing. But I just think there's so much that's unknown'. (F01P, 62 years)

No more information needed

There were a number of participants who were satisfied with the amount of information they had been given, with a few patients giving examples of all their questions being answered.

'He [doctor] said, "But if there's nothing on there, there's no answer to your question, write it down on a piece of paper, bring it in and ask me." And that's what I did. And he just answered everything completely, completely'. (M22, 59 years)

Some participants also did not want any more information because they did not want to know the details of what they were going to go through and they did not want to get frightened. One partner also believed that 'sometimes too much information is bad, because you're looking for the things to occur'. (M61P, 74 years)

8.4.6 Psychosocial impact of the diagnosis and treatment

Patients discussed in detail many psychosocial aspects of their diagnosis that were not directly related to having HPV. In some cases, HPV did play a role in this (e.g. by influencing prognosis), but largely these aspects were related to dealing with a cancer regardless of the cause. As the previous research in chapter 2 illustrated, there are a number of factors which

can influence the psychological impact of HNC and so it was important to discuss those brought up by participants. This theme represents all the ways in which participants discussed the cancer diagnosis had a psychosocial impact on them. Subthemes that relate directly to the research question include psychological responses, feelings of the patient's partners, partners taking control, social, work, having a different perspective on life and feelings about the future.

Responses to the diagnosis

This was a major theme that included a variety of responses from patients and their partners.

Accepting it and getting on with it were common responses:

'But anyway, that's, you know, we had to... you've got to take it, haven't you, one step at a time. Accept it, fight it and pray that everything is gonna be all right. That's all you can do. With any cancer it's a shock but you've got it and what can you do about it? Accept it and be positive that this will... the cure, he'll have the cure, he'll have the treatment. So far, so good'. (F50P, 73 years)

There was a mix of trying to be positive and not being frightened about the diagnosis, with others not feeling sure they would survive and wondering if they would see their children grow up. Some patients described cancer as a 'battle' and how the diagnosis had been a 'blur' and they had 'blanked it out'. Cancer was still perceived as a 'scary word', with one patient saying, 'it's like, kind of, Voldemort, you know what I mean, you're not allowed to say the word, it's, it's like so powerful and no one can joke about it' (M9, 49 years). Patients described having dark times, being in denial and having depression and anxiety.

'But, um, I did have a few dark times, you know, waking up in the middle of the night and saying, "Oh, I've had enough now." Because, um... There was one particular day where I just woke up and burst into tears in the middle of the morning, which I don't normally do. I said, I've just had enough. Sleep deprivation and everything else, treatment and feeling rough'. (M47, 49 years)

Other feelings expressed by patients and their partners included feeling alone or isolated, forgetting about cancer for a while, embarrassment over how things had changed, relief about clear results, stress and trying to go on as normal. A couple of patients also expressed that they had trouble sleeping due to the stresses associated with their cancer diagnosis. Some participants expressed that they felt lucky:

'You've come out the other side. You've been lucky. You've been unlucky, but lucky'. (M59, 56 years)

Feeling that nothing is normal anymore was described by some participants, as well as expectations from other people and unrealistic expectations about how long the recovery would take were also described by some patients.

Loss of confidence was described by a few participants, with this one partner describing losing confidence in her partner's health and in his ability to do things:

'And I think it has knocked me confidence a bit really, because I didn't think he was invincible as such, but with coming out of the blue, you know, it just wasn't expecting it'. (F31P, 56 years)

Appearance was a worry for some participants; not knowing what they were going to look like after the treatment. One partner said he 'went a bit cold then because I thought a lady does not like to have a disfigured face, and especially [name of patient]' (M61P, 74 years).

A few participants had 'a fear of the unknown' and 'didn't have a clue what really was going on'. One patient described not knowing what was going on as being the hardest bit.

Partners: Feelings about their partners' cancer

One partner explained how he felt inadequate when his wife came home, as he did not know what to do. Partners also wanted to protect the patient and their children by being strong and not showing when they were upset. Another partner described how his partner (the patient) was worrying more about him and how he had taken control and things had been excellent since she had come home from hospital, demonstrating a positive effect of his caregiving role empowering him to be more independent.

'I then got myself ready for when she came home, and things have been fine since she has been home. Um, I'm not drinking so, um, that's fine. Um, but things have been very good since she's been back. Yes, excellent, I would say'. (M55P, 58 years)

Partners also described the difficulties around HNC being 'a dreadful illness' and other people lacking understanding.

'And when the, um, when the treatment finished, people, it, it, that was something that was quite interesting actually, that er, just occurred to me, all the time [name of patient] was having his treatment it was as though, [name of patient]'s got cancer now. When his treatment finished, some people just thought that's it, he's, he's, that's it, it's done, so it's, which was quite interesting. Then, you know, again that's just, it wasn't that they didn't care, it was just lack of, um, their understanding'. (F10P, 60 years)

Seeking further support, such as through Macmillan, was at times considered by a couple of partners.

'I felt worse... I felt... started feeling worse and I didn't know... I was on the point of... I was just bursting into tears, and I was on the point of ringing the Macmillan support line to talk to somebody because I was thinking, well, why am I feeling like this, he's getting better'. (F31P, 56 years)

One patient explained how she was made to feel like she was 'in the way' and was treated as though she 'wasn't there' when she was with her partner at the hospital.

'And like sometimes I've tried to ask questions, and they look at you as if to say it's not you that's got the cancer, it's him. It's just get out, just out of the way. And I've felt like that a lot of times ... And then when, um, when he was going, going, when he was going for the diagnosis and things like that, I was going with him, and I was just, they was just treating me as if, as if I wasn't there'. (F37P, 61 years)

Partners: Taking control

Partners described ways in which they took control by 'dragging' patients out of the house to go for treatment and searching for as much information as possible:

'I had to make him go. You know, "I'm dragging you out of the house for more treatment. But, err, no, I suppose I saw the bits that people didn't see. The times when really, he just didn't want to do anything. "I'm not going. I'm not going to [name of cancer centre] today." "Yes you are." So then I had to say something different to yesterday [laughs]. "Yes, you are coming to the car." (F56P, 59 years)

Partners were also influential when it came to the patient going back to work. One partner was not happy about her husband going back to work, believing he had gone back too early. She also said:

'But, I says, "If you can't eat," I says, "You can't drive." Because he works in [name of town], you know, so he's got 100 miles a day to drive, if he's not eating as well, so. So I sort of, "No you can't, until you can actually eat properly. Have breakfast, bit of dinner, something for tea." So that was me putting my foot down!' (F56P, 59 years)

One of the patients also wanted to return to work after he had been diagnosed but this partner stopped him:

'And he thought he was going to continue going back out to work and I'd always say, "Ha-ha, no you're not! You're going to sick health," cause this was on, sort of, the Friday, "you're going sick Monday morning." (F06P, 64 years)

Social

Some of the negative impacts of the diagnosis included having to cancel things such as holidays, not being able to cook like they used to and not being able to do the things they loved doing. One patient did not want to be treated differently socially as a consequence of his diagnosis:

‘And I found that really oppressive, I couldn’t stand the fact that I was out, people weren’t taking the mickey out of me, I really wanted people to take the mickey out of me and treat it lightly, and it’s, you know, just like other things in life and, you know, people joke about death and lots of other things’. (M9, 49 years)

The most common way in which participants spoke about their social life being negatively affected was through the effect of the treatment on eating and drinking, as this reduced their desire to eat out and in front of other people, therefore they felt it was ‘a waste of money’:

‘Everything affects your social life, seriously, because, let’s be honest, when he was ill he got tired very quickly, so you couldn’t go far really, and he couldn’t have a drink. He’ll tell you the first gin and tonic he had was just like soap’. (F50P, 73 years)

One partner described how it affected her social plans as she did not spend as long out of the house as she used to:

‘And as for social life, not really, we still go to the theatre, um, and I still go for lunch with my friends, but I tend to only be away a couple of hours, whereas if I’d gone for lunch with friends, I’d probably go shop, around the shops, but now I’ll... I probably go out nearly every day for a couple of hours, because [name of patient] reads the paper from... every single word. So I thought, well, I might as well be out’. (F50P, 73 years)

Some participants described how their diagnosis had an effect on their hobbies, with one patient saying ‘swimming was the furthest thing from my mind’ (F13, 42 years).

‘Well, initially, after all me treatments... we’re strong rugby league fans, [name of hospital], and we go home and away games. We go all the away games of a weekend, and I couldn’t do that at the time because I couldn’t eat. I was having milk, and I couldn’t... I sort of couldn’t be anywhere away from these protein drinks, and I couldn’t physically take them all with me. [Laughter] I’d be going round with a suitcase as if I was going on holiday. So, a big impact, social-wise, erm, but I didn’t want to go out anyway. I just wanted to sit in here and...’ (M59, 56 years)

One patient said that he is not a sociable person anyway so it did not affect him too much. Two patients described how it paused their hobbies temporarily but that they are doing them again now, with one patient saying he is playing golf more now than he was before.

A positive impact reported was the opportunity to spend time with family; however some had so many visits from friends and family that, at times, they just wanted to be left alone.

Work

Work came up in a lot of the interviews, primarily as this was something that was impacted upon in the majority of cases (for those who were still working and not retired). Some of the patients described how they enjoyed going to work and the normality of it, how they liked 'having that purpose', how the money gives them some freedom and keeps them occupied, with some describing being bored without work.

'Well, the treatment had finished, it was like it's either sit round the house or get, get back to work sort of thing. And, as far as I was concerned, that bit's done now, let's get back, life back to normal, look forwards and carry on'. (M56, 61 years)

Work was seen as a distraction from their partner's treatment for a couple of the partners, to 'keep busy' and 'take your attention'. A number of the patients and partners described how they stopped working after their diagnosis or their partner's diagnosis. In some cases, the patients were not able to return to their same job following effects of their treatment.

'Erm, certainly work-wise, er, 'cause I work on the gas industry. And because I've no saliva glands now on this side, I've always got water to... and gels to keep me mouth lubricated. Erm, you wear breathing apparatus if you're working in a gaseous atmosphere and I can't do that now, so I can't fulfil that side of my job'. (M59, 56 years)

Two partners described how they were not able to do the same job as they had previously worked with cancer patients and it was too close to home now.

'I work in a GP surgery, I'm a nurse, and part of my role is, um, every month we have a monthly meeting, err, with patients with cancer and end of life and I always used to take the minutes and things like that. Well, I've, I've not been in since because I can't, it's too close to home'. (F31P, 56 years)

Another partner who had worked with cancer patients described some of her experiences and how it had helped.

'So, yes, so yes I think it did help in some ways, you know. Uhm, perhaps if I hadn't had all those experiences I would have been more scared, but I wasn't, cause I saw so many people live with cancer for a lot of years and – and live with it and continue working and doing everything else in their normal lives. So I knew that we were on that same road'. (F06P, 64 years)

Another partner described how she was pleased when she was able to go back to work and how 'work ethic's very important' and that she's much happier now she's back at work.

Two of the partners described continuing working, but one ended up being signed off work with stress, later returning to work part-time.

'I worked with a particularly challenging pupil at the time and it kind of pushed me over the edge and I broke down in work and I got fetched home ... In a nutshell, I basically ended up being off work for three months. The doctor signed me off with stress'. (F59P, 49 years)

Feelings about work were a mixture of patients missing their friends at work, thinking that their health is more important than work and wanting to go back to work as soon as the treatment had finished. One patient described how he could not wait to retire and how he does not 'go for the love of it'.

A different perspective on life

Some of the participants described how the diagnosis had given them 'a different perspective on life', most of these being positive. A couple of patients explained how they were now more focused on and more aware of their health.

'So yeah, just a general acknowledgement that your body is, you know, more fragile than you realise and needs to be looked after probably more than it did when you were young and you were doing before you got ill, so yeah, just a general keeping healthy and, you know, just keeping it going'. (M9, 49 years)

One partner described how she now felt 'more empathetic' towards cancer patients, as she could now understand more about what they were going through. Some participants also described themselves as being 'a better person' and how they appreciate things more since the cancer diagnosis.

'It's totally changed my way of thinking about life. You know, and, err, I suppose in some respects for the better because sometimes you can be a bit cruel or, you know, you see somebody walking past and they drop something, "Oh, let them pick it up." Or they don't notice. But now I don't, I stop somebody'. (M22, 59 years)

The realisation that life is short was brought up by many of the participants, that you have to enjoy it, not worry about the cancer, do things you want to do and 'get on with it'. One patient also described how cancer had 'made me harder ... life's too short to fill it with A holes' (F13, 42 years).

Feelings about the future

Most of the patients and their partners were positive about the future, making plans and looking forward to the future.

‘Err, pretty optimistic really. Yeah. As I say, even more so since, you know, being told that the prognosis is much better, um, for somebody with, you know, oral cancer, if it is HPV-related. But yes, um, [pause] you know, as I say, I’ve never, I’ve never had a thought that it’s a terminal thing. So yeah, you know, quite optimistic for the future’. (M31, 61 years)

Two patients were not as positive about the future, one feeling like they cannot plan ahead and the other feeling like the future was bleak.

‘Umm, yeah, umm, I suppose we all, without thinking about it, plan things ahead constantly, and you can’t at all. Or you feel like you can’t, you know’. (F58, 61 years)

Fear of recurrence was common among patients and their partners. This was sometimes related to HPV, such as this patient wondering ‘is it [HPV] more likely to come back because of this? Is it something that stays in your body?’ (F58, 61 years)

8.4.7 Impact on others

This theme covers the impact that the patient’s cancer diagnosis had on their family and more specifically their partner.

Impact on family members

Patients described the reactions of family members being that of devastation, scared, worry, upset, concern, shock and being stoic. Many of the patients brought up the effect on their children and grandchildren:

‘My daughter handled it pretty well, I think my son was affected by it a bit, he, he felt that I was a kind of a superman before that, you know, I was, I was a big bear and, you know, kind of, you know, really, really kind of invincible and that whole period made me very, you know, mortal’. (M9, 49 years)

Participants with children mainly talked about the effect on their children, with older children being supportive and wanting to be involved, and those with younger children advocating being honest with them. One patient tried to keep herself away from her children as she was visibly deteriorating.

One couple described the diagnosis as having a positive effect in that it 'brought family more together' and that previous conflict in the family got resolved and their daughter 'started speaking to us again'.

There were some stories of arguments between family members and mealtimes were especially stressful between the patient and their partner, as the partner would prepare food and the patient could not eat it.

'She had to try and cook food, which I couldn't manage to eat because my mouth was obviously sore. And of course we had rows about that, because I never got the things which... well, not never'. (M50, 83 years)

Preparing food and eating were described as some of the most stressful experiences. Partners struggled finding things that the patients would eat and then one partner explained that '[the patient] would get fed up eating the same thing' (F58, 61 years). Loss of appetite, the struggle eating, intermittent taste and dry mouth were described as the worst parts of the cancer. This partner describes how she used to prepare her husband's food.

'And on a Sunday, well that was hilarious because [clears throat] we kept trying to keep to the roast dinner ... mine was in the oven, and I bought, what you call a Bullet. Have you ever heard...? I bought a Bullet, which you can make into smoothies, and I also bought a hand mixer as well to get the food pulped down. Anything to get the food, so that he could just take it off a teaspoon. Mmm. It wasn't, it wasn't easy at all'. (F50P, 73 years)

Effect on partner

One of the evident impacts of patients' partners was them becoming a carer and spending an increasing amount of time at home. Partners described their experiences as a carer as 'doing the mum bit', being 'bossy', caring for them and taking them to their treatment appointments. A few of the partners saw it as their role and they did not want anyone else to take them:

'I didn't want anybody else doing it. I know that sounds a bit weird, but... I knew what he was gonna go through, or imagined what he was gonna go through, and I thought that is the one thing I could do. I could take him'. (F56P, 59 years)

Patients recognised the impact that their diagnosis had on their partner, recognising that it was hard for them, that they were worried and that they were tired and 'run-down'. One patient recognised that with her partner 'there's definitely issues there, but we've got different issues' (F13, 42 years) and that her partner did not want her to get involved as a cancer support

worker. Another patient recognised that ‘she needs more support than me, if you know what I mean’ (M10, 63 years).

Partners expressed the effect it had on the patients’ weight, their sleep and how upsetting it was.

‘And sometimes I would be thinking to myself, [name of patient] was very quiet because his throat hurt all the time, he didn’t do much talking, um, and sometimes I think, well how am I, how am I doing this every day, because it was very tiring, it was six weeks. But you kind of do, just get on with it’. (F10P, 60 years)

For one partner, his wife’s diagnosis amplified some psychological problems, saying ‘I was [pause] distressed like I’ve never been distressed before’. But it also had a positive impact on him regarding him becoming more independent, getting a bus pass and his driving licence back in preparation for his wife coming out of hospital. He saw himself as ‘quite a positive person now’.

There was recognition that the diagnosis affected both of them, but that sometimes the patient just wanted to be left alone.

8.4.8 Case studies

As the data interpreted through framework analysis have many cross-cutting themes, two case studies have been chosen to illustrate the way in which patients reacted differently to their diagnosis of HPV-OSCC and how this impacted upon them. They have been selected as they represent contrasting experiences and reactions of testing positive for HPV.

Case study 1

The first patient is a 42 year-old woman who is married, with four children and is employed part-time. Her partner was not interviewed as he does not want to talk about her cancer and ‘he kind of wants to put it in a box and put the lid on’. She was in a previous marriage before marrying her current partner. She described being shocked that she could have HPV, ‘felt dirty’ and was worried that she had passed HPV onto her partner. She described feeling very unlucky and worried about issues that an HPV diagnosis caused in her relationship with her husband, with her husband making her ‘feel dirty’ about the fact that HPV is sexually transmitted. She was

reassured by information given to her by her oncologist about HPV being the most contagious virus in the world and in a small number of people HPV turns into cancer.

Reluctance to tell others that her cancer was caused by HPV was demonstrated because she did not believe it was anyone else's business and even though she still has 'a bit of an issue' with having HPV because of the stigma attached to HPV by other people, she is now more open about HPV with the information she has been given by her oncologist. A friend who worked in a hospital reassured her that other people will not think that HPV is down to oral sex and if they do then it is due to their naivety.

Concerns about the HPV vaccine not being offered to boys were expressed, as she has two sons and believes it is unfair that boys are not vaccinated. She had looked at getting her older son vaccinated privately.

This patient did not mention any information she was given about the prognosis of her cancer. She found the medical staff very informative about what she wanted to know about HPV and the treatment for her cancer. Her husband was also kept well informed. She was not told information about HPV at her diagnosis and would have preferred to have heard information about HPV when she was diagnosed. After she had been told about HPV, she had looked HPV up on the internet and described 'breaking down' as all the information on the internet said that HPV was all because of oral sex. This patient also mentioned Michael Douglas and how he had contributed to the stigma attached to the diagnosis of HPV-OSCC.

Case study 2

The second patient is a 61 year-old man who has been married for 34 years, with two children and is retired. He described not feeling shocked about being diagnosed with cancer and never felt he was going to die. He was not concerned about the cause of his cancer and the most important thing was that his cancer had gone. He had not even thought about HPV being the cause. He would have liked to have been told about HPV being the cause of his cancer right at the beginning because he believes in honesty. His wife suggested a good time for them to have been told about HPV would have been at one of the follow-ups after they found HPV. He did not disclose HPV as the cause of his cancer to others and nobody had asked, but was honest and kept his children up-to-date about his treatment. His wife explained how they had told their

children about taking part in the research, but not disclosed that it was because his cancer was HPV-related, mainly due to not wanting to 'bring it all up again for them'.

Being told the prognosis was much better for HPV-OSCC, this patient and his wife felt optimistic about the future. He was reassured by the prognosis being better and felt happier once he had been told this. His wife felt a sense of relief when they found out that his cancer being HPV-related meant that the prognosis was better.

Information the patient described being given about HPV included that he could have had it for years, but was not concerned about how he had got HPV as he had been with his wife for 34 years and was secure in the knowledge that neither of them had ever been with anyone else. The partner also recounted that they were told that it is very unlikely that HPV would be passed on to her as 'usually the virus disappears'. The internet was used to look up information about HPV and he learned that most people get rid of the virus, but that in some people it does not go away like it would normally. This information was confirmed by the doctor. Questions he had about HPV included whether he was still carrying the virus and whether that means it can come back. Michael Douglas was also mentioned by this patient and his wife; the patient was not aware of what he had said about HPV and throat cancer, but his wife believed Michael Douglas' disclosure did not help. His wife had some understanding about HPV already, but described having any questions they did have, answered by the doctor.

These two case studies illustrate the different ways that people respond to a diagnosis of HPV and the possible implications that this might have. Although both patients were aware of the sexually transmitted nature of HPV, the first patient experienced emotional responses of shock, worry and stigma and the second patient was not concerned about HPV, and was secure in the knowledge that neither he nor his wife had been unfaithful. The first patient also focused more on the suggestion of HPV having been transmitted through oral sex, whereas this was not specifically mentioned by the second patient. These differing reactions to HPV may be due to the differences in their life circumstances, with the first patient being married for a second time, being younger, female and having four young children, compared to the second patient who has been married for 34 years, is older, male and has two grown up children. Both patients would have liked to have been told about HPV as soon as they had been diagnosed. Both patients had looked for HPV information on the internet, with the first patient 'breaking down' when it was

suggested that oral HPV was transmitted through oral sex, whereas the second patient was reassured by the information that the prognosis was better.

8.5 Discussion

This study explored the psychosocial impact of being diagnosed with HPV-OSCC for patients and their partners. The demographics of the sample were representative of the 'typical' HPV-OSCC patient, being mostly male, married, a median age of 57 at diagnosis and white (Gillison et al., 2008; Marur et al., 2010). The youngest patient was diagnosed at 40 years of age, reflecting the younger age of these patients. Although the medical records of all patients showed their tumour was HPV-positive, not all the patients were informed of this. Reactions were mixed among those who knew their cancer was caused by HPV. Some participants felt embarrassed and recognised stigma associated with HPV. Other participants were not concerned about the cause of their cancer and were more interested in knowing the survival rates were better and they were going to get better, suggesting concerns were more cancer-related than HPV-related. The two case studies presented suggest that these differing reactions may be due to life circumstances. Patients and partners who were told about HPV as the cause had a number of questions about HPV and some sought out further information. Psychosocial effects were similar to those described in previous qualitative research with HNC patients (Baxi et al., 2012; De Boer et al., 1999; Lang et al., 2013), with patients describing times of depression, anxiety and denial, but also feelings of optimism and relief.

Participants reactions to finding out that their HNC was caused by HPV varied. In line with findings from the cervical cancer literature, some patients reported feelings of embarrassment, confusion and concerns of transmission to their partner (McCaffery et al., 2006). As reported in chapter 6 by health professionals, there was also concern among patients who had young children, boys in particular, about them being more at risk of HPV and not receiving the HPV vaccination as part of the national immunisation programme. One couple had paid to have the vaccine themselves after concerns about transmission, with evidence now emerging that the vaccine can help prevent future infections or infections with different HPV types (Joura et al., 2012). Michael Douglas was also mentioned, and supporting findings from chapter 5, participants perceived what he had said as unhelpful and that it had also added a 'sensationalist aspect' to HPV-OSCC. This had changed one of the partner's attitudes about being so open

about the diagnosis, and others described giving factual information about HPV being the cause when discussing with others, suggesting they were trying to avoid attaching stigma to it.

Supporting the key messages from chapter 6 where health professionals expressed the importance of normalising HPV, patients reported health professionals relating HPV back to cervical cancer and normalising HPV by telling them it is becoming more and more common and that it seems to affect anybody. Some participants did search for more information about HPV and found that the information available was not applicable to them and was targeted at young girls in relation to the HPV vaccination. Information sought from patients and their partners about HPV was specific about where HPV had come from and around transmission and future HPV risk, supporting previous research which showed 62 HPV-OSCC patients sought causal information and information about vaccinations, prevention of transmission and available treatments (Milbury et al., 2013). The internet was a popular source of information for participants, which has been found previously in this population (Baxi et al., 2012) although patients did recognise that the information is not always trustworthy and reliable. Findings from a previous study with the same population showed patients wanted more information about HPV and that 'a cohesive, comprehensive, and trusted source would be valuable' (Baxi et al., 2012, p5). These findings suggest that there is a need for information to be available about HPV and HNC which is targeted at these patients and developed in line with evidence-based research. Previous research in the USA has confirmed that less than half of oncologists discuss HPV with their patients (Milbury et al., 2013) and this study showed just over half had been told of their HPV diagnosis. As it is becoming more recognised that patients should be informed about HPV being the cause of their cancer (Shuman & Wolf, 2010), health professionals need to decide on the best time to discuss this with patients, with patients in this study suggesting the earlier the better.

Previous research with a small sample of male HPV-OSCC survivors also found that HPV was often overshadowed by the cancer itself and that patients were encouraged by the positive prognosis (Baxi et al., 2012). Unlike previous studies (Baxi et al., 2012; Low et al., 2009; Manne & Badr, 2008), no patients or partners in this study reported decreases in intimacy, but this may be because they were not specifically probed about their sexual relationships. Similarly, both studies showed HPV to be relevant, but that this was secondary to the concerns about treatment of their cancer.

Findings from my systematic review in chapter 4 showed mixed results for the psychological impact of HPV-OSCC, with these studies mainly comparing QOL between HPV-positive HNC and HPV-negative HNC patients. The results from this study show the impact of the cancer diagnosis itself and the impact of the treatment are still significant for HPV-positive patients. One study from the systematic review showed the 'social' domain on a measure of QOL to reach its lowest at 3 months (Dziegielewski et al., 2013). This is the time when patients are receiving treatment, and patients in this study described being unable to and did not want to eat out or be sociable due to issues with eating, talking and being tired.

The Transactional Model of Stress and Coping could be a useful framework to consider when designing further studies with this patient group to understand how patients appraise their diagnosis of HPV-OSCC, and this model has been used previously with cancer patients to examine psychological adjustment to cancer (e.g. Hulbert-Williams, 2009; Parelkar, Thompson, Kaw, Miner, & Stein, 2013). In the context of these results, the way in which a patient appraises their diagnosis of HPV-OSCC (the stressor) influences their method of coping, which impacts upon their adjustment to their diagnosis. Perceptions about the severity of the diagnosis, how much this will impact their life and how much they perceive themselves to blame for their diagnosis are all elements of primary appraisal in these patients. The amount of perceived control over the outcomes and emotions, as well as their confidence in their ability to deal with their diagnosis are all secondary appraisals which also influence the patient's choice of coping strategy. Social support can moderate the secondary appraisals of patients and a study with HNC patients found those with less social support adopted less effective coping strategies (Moore et al., 2014). It is likely that HPV-OSCC patients will perceive high motivational relevance and there could also be the potential for some patients to have a high causal focus if they perceive their diagnosis to be a result of their sexual behaviour. It may be possible that patients' appraisals of a diagnosis of HPV-OSCC could be adapted as a result of the information presented to them by health professionals, such as by using the key messages from chapter 6. For example, informing patients of the better prognosis and that HPV is a result of normal sexual behaviour may reduce patients' motivational relevance, causal focus and also increase their perceived control over their diagnosis.

The impact of an HPV-OSCC diagnosis on patients' partners was significant. Many of these partners had to stop working and become a carer for their partner, feeling it was their role,

supporting findings from previous research interviewing 31 caregivers in Ireland that identified 'lifestyle restrictions and competing demands' and 'financial problems' (e.g. as a consequence of having to give up work) as two relevant themes associated with psychological distress (Balfe et al., 2016). Partners were also often the source of information for others, being the one who had to keep the rest of the family informed about the patient. Partners also sought information about HPV and other aspects of their partners' cancer, in the effort to be as prepared as they could be, supporting previous findings from a study in New Zealand with 73 caregivers that found in a need to improve their understanding of the situation, caregivers requested information (Richardson et al., 2015a). Partners also thought about others, trying to hide their feelings from either the patient or the rest of their family. Patients recognised that their diagnosis had a significant impact on their partners, which supports previous findings from two studies in New Zealand carried out with HNC patients and their caregivers (Richardson et al., 2015a; Richardson, Morton, & Broadbent, 2015b). The findings from this study also support previous research with partners and carers of patients with HNC who have found carers to report restrictions to their lifestyle and frustrations around providing food for the patient at home (Balfe et al., 2016; Longacre et al., 2012).

8.6 Strengths and limitations

This study is the first in the UK to interview patients diagnosed with HPV-OSCC, as well as their partners. By interviewing patients and partners separately, this enabled each individual to share their experiences from their own perspective without being influenced by their partner. By interviewing both patients and their partners, this also allowed me to capture the individual within the dyad, without taking into consideration the perspective from the dyad (Eisikovits & Koren, 2010). This method also allowed me to address HPV, which may have been too sensitive to bring up in joint interviews. Other approaches which could be taken to interviewing these dyads include conducting two separate simultaneous interviews, conducted by different interviewers; joint interviews; both separate and joint interviews with the same participants; and separate interviews with some dyads and joint interviews with others (Eisikovits & Koren, 2010). Due to time and cost constraints, the simultaneous separate interviews and the combination of separate and joint interviews, were not possible. As I was not aiming to analyse interactions

between the patient and their partner, joint interviews were not appropriate, as well as for reasons of sensitivity of the topic.

As I was a stranger to these participants and they were interviewed in a naturalistic setting, this may have enabled participants to feel more comfortable disclosing details about their experiences. Qualitative research provides a wealth of rich data, a lot of which could not be presented in this chapter. Qualitative interviews give a much greater depth to providing an understanding and description of people's personal experiences.

There were a number of ethical considerations which limited part of the research design for this study. Although all patients had been screened as HPV-positive on the basis of their medical records, not all these patients had been told of their HPV status, despite having indicated this on a pre-screening questionnaire. These discrepancies have been found previously in this population, where 62 patients were identified by their medical records as having an HPV-positive tumour, but only 66% of the patients reported that they had an HPV-positive tumour (Milbury et al., 2013). This limited the scope of some of the interviews, as HPV could not be discussed as it would not have been ethical for me to disclose this to them. There is also the ethical problem of presenting quotes of participants alongside their partner's quotes, revealing information which has been conducted in confidential interviews (Forbat & Henderson, 2003), but I have taken efforts to avoid doing this. Although the interviews were conducted separately, it is possible that patients and their partners may have discussed the interview between the interviews being arranged and when it was conducted, which may have influenced their response. Conversely, this may have triggered some memories in the participants which they may have otherwise forgotten. Conducting the interviews separately ensured that the participants would not interact within the interviews, but this may not have stopped the patient thinking about their partner when giving their responses during the interview. As with any qualitative research, the results cannot be generalised due to the sample size and recruitment being non-random, although the data in this study did reach saturation and no further themes were emerging. The interpretation of the data can also be influenced by the researcher, but by including others in the analysis process, it is hoped that this will have minimised any personal biases and idiosyncrasies. There is also the limitation of time since diagnosis with these patients. Patients were interviewed at least one year post diagnosis to ensure that they were post-treatment and were now in recovery. This may have affected the results in that issues

pertinent to the participants at the time of diagnosis may no longer be pertinent now, or they may have forgotten their feelings at the time of diagnosis. It is not possible to know whether the responses of these patients at one year would be similar to those patients who may not have survived for one year. However, given the survival rates for HPV-OSCC patients are good, it is hoped that most patients would survive at least one year.

8.7 Conclusion

This study suggests that HPV-OSCC has a significant psychosocial impact on patients and their partners, but that most of the concerns are related to dysfunction that occurs from their cancer treatment and not to their HPV status. There are concerns and uncertainties about the sexually transmitted nature of HPV which need to be addressed and this information should come from a trustworthy and reliable source such as the patient's doctor. As participants used the internet as an information resource for HPV, written information for patients and their partners is likely to be a useful resource and from a resource that is trustworthy, which leads to my final study. This written information should be discussed with the patient around the time of diagnosis. Further work is needed with a larger number of HPV-OSCC patients across different time points in their treatment pathway to establish their immediate responses to HPV and their feelings at different time points.

CHAPTER 9. THE DEVELOPMENT OF PATIENT INFORMATION MATERIALS (STUDY 6)

9.1 Introduction

Communicating health information can be challenging (US Department of Health and Human Services, 2009). The previous chapters of this thesis have shown some health professionals to have a lack of confidence in discussing HPV with oropharyngeal squamous cell carcinoma (OSCC) patients (see chapters 6 and 7) and also that patients search for answers to questions they have about HPV (see chapter 8). Health professionals have also responded positively to the idea of having a clear plan of what to say to their patients about HPV and also welcomed the idea of having a leaflet that can be used with patients (see chapters 6 and 7). As previous research with HPV and cervical cancer has shown that there are key pieces of information about HPV that help reduce negative psychological consequences (see chapter 3), it is important that these messages are also communicated with HPV-OSCC patients. This chapter will use the term OSCC as the information developed is specifically aimed at HPV-OSCC patients. The term throat cancer is used in the information for reasons explained in the development process.

There is substantial evidence that chronically ill and cancer patients obtain health information from sources other than physicians (Czaja, Manfredi, & Price, 2003; Wagner, Baker, Bundorf, & Singer, 2004). In a small USA study of 62 HNC patients, 58% of HPV-OSCC patients reported seeking information from sources other than their oncologist (Milbury et al., 2013). Since the introduction of the internet, a substantial number of people now use it to search for health information. In the UK, the use of the internet to access health information has risen from 18% in 2007 to 49% in 2015 (Office of National Statistics, 2015). The rates have been found to be even higher in the USA, with 72% of internet users reporting looking online for health information in the last year (PewResearchCenter, 2013) and in rural Canada the internet was reported to be frequently consulted for health information by 59% of responders (Harris, Wathan, & Fear, 2006). Searching online has been reported to improve people's understanding of health care issues (Baker, Wagner, Singer, & Bundorf, 2003) and empower patients as a result of increasing their knowledge (Ziebland et al., 2004). However, there is the problem of

inaccuracies associated with information found on the internet and difficulties in finding high quality websites (Eysenbach, Powell, Kuss, & Sa, 2002). In contrast to printed educational materials, information on the internet can also be found across a number of different web pages and not on one website alone. The information found on the internet may also require higher literacy than printed educational materials (Eysenbach et al., 2002). Health information on the internet therefore may present inaccurate information which is not written at accessible readability levels and may cause unnecessary patient anxiety.

Although the internet is becoming a huge resource of health information, it is still not used by all as a source for health information. Health professionals remain an important and a trusted source of health information and patient information leaflets are important in healthcare (Garner, Ning, & Francis, 2012). The Pew Internet Project found 70% of US adults still received information from their doctor the last time they had a serious health issue (PewResearchCenter, 2013). Health professionals have an important role to play in checking patient comprehension and initiating an open discussion about health information (Colledge, Car, Donnelly, & Majeed, 2008). Written information is still important to ensure that those who are without access to the internet and other new technologies are not unduly disadvantaged (Eng et al., 1998; Hsu et al., 2005). Those more likely to use the internet to seek health information are younger, female and have more education (Bundorf, Wagner, Singer, & Baker, 2006). The 2004 UK White Paper 'Better information, better choices, better health' stated that 'everyone should have improved access to high quality information, health professionals should communicate more effectively with patients and there should be a nationally coordinated process to produce and deliver info' (Colledge et al., 2008, p447).

Health literacy is an important determinant of patients' understanding of information given to them, and the percentage of adults in the UK below the literacy level expected at 16 years of age has been reported to be 43% (Harding et al., 2012), with the same percentage without the literacy skills to be able to understand the text in health materials (Rowlands et al., 2015).

Good information provided to patients following the consultation can help remind patients what they have been told if, due to stress or language difficulties, they are unable to remember. By providing this information, it also gives patients the opportunity to go away and read the information that is relevant to them and think about the issues involved. Good information can

reduce patient anxiety, increase understanding of their diagnosis and result in patients being more satisfied with their care (Ong, de Haes, Hoos, & Lammes, 1995; Stewart, 1995). This information can also be useful for patients' partners and other family members. High quality information is a key aspect of support for cancer patients and their families and as shown in chapter 8, caregivers search for information about the diagnosis.

Previous experimental studies communicating HPV in the cervical cancer context have found key messages important to be communicated (Lloyd, Marlow, Waller, Miles, & Wardle, 2009; Waller et al., 2007). A study with female students randomised to receive information about HPV, Chlamydia or the environment, found that although HPV information was rated as more scary, it was also rated as more reassuring than environmental information and did not increase anxiety (Lloyd et al., 2009). A study manipulating knowledge of HPV in four experimental conditions found participants receiving messages about the high prevalence of HPV rated lower stigma and anxiety compared to participants who only received information about the sexually transmitted nature of HPV (Waller et al., 2007). Shame was also rated higher in this group compared to all other groups. The group with lowest anxiety was the group receiving basic facts about HPV, its high prevalence and its sexually transmitted nature. Lower stigma and shame scores in those receiving the messages about the high prevalence suggest there may be a normalising effect associated with this information. As these studies were either hypothetical or in student samples, it is not possible to know if these can be generalised to a clinical setting. However these studies provide important findings as to what messages about HPV may be best received and may mitigate negative psychological consequences associated with its sexually transmitted nature.

Information currently available

When conducting a Google search online using an incognito window for 'HPV', the top links were for NHS Choices, Cancer Research UK, Wikipedia, Centers for Disease Control and Prevention, Macmillan, Jo's Trust, and the National Cancer Institute. All these links were mostly in the context of cervical cancer, with the National Cancer Institute including oropharyngeal cancer as a cancer caused by HPV. Information materials available through some of these links include titles such as '*Human Papillomavirus (HPV)*' published by Jo's Trust and '*The HPV Vaccine*' published by the NHS. These information materials included information about the

prevalence of HPV, how HPV is transmitted, reducing the risk of having persistent HPV infection, HPV and cervical cancer, cervical screening and the HPV vaccine. The NHS booklet about the HPV vaccine also presented more detailed information about the vaccine, including who is eligible and potential side effects.

When searching online for ‘head and neck cancer’, the information available from Macmillan, NHS Choices, Wikipedia, the National Cancer Institute and Cancer Research UK was presented on the first page of results. This is general information, such as ‘*Mouth Cancer*’ published by Cancer Research UK and there is also a wealth of information online, with some hospital trusts having information on their websites (e.g. Liverpool Head and Neck Centre, University Hospitals of Leicester). As found in the previous chapter, a lot of the information provided to patients was around their treatment. Some websites have begun to acknowledge the role of HPV in HNC, but there is either still a lot of information lacking from these websites, or the information provided is not targeted at the right readability and comprehension levels.

Conducting an online search for ‘HPV and head and neck cancer’ uncovered a questions and answers leaflet resource from the USA based on a peer-reviewed paper (Fakhry & D’Souza, 2013). This was a comprehensive leaflet, but was all text and does not include diagrams. Although it included some basic information about HPV, this was incomplete. Many of the other results from this search however, included links to research papers which were not understandable to all users. Specific UK-based charity websites were not easily found during this search and only when ‘HPV and throat cancer’ was searched for did The Mouth Cancer Foundation become evident, suggesting UK-based HNC charities do not use the terms commonly enough for them to be picked up as keywords.

Information booklets have begun to be developed in the UK about HPV and its relationship with HNC, but these were not always appropriate in communicating messages that are aimed at reducing any possible negative psychological consequences. An example is ‘*HPV and Mouth Cancer*’ published by The Mouth Cancer Foundation, which included information about what HPV is, HPV and mouth cancer, getting HPV and the HPV vaccination. The leaflet provided a quote which says, ‘The only currently available preventive measure is to practise sensible sexual behaviour’. This has the potential to suggest that those who have HPV-OSCC had not been practising ‘sensible sexual behaviour’. The Throat Cancer Foundation website gives

information on what is HPV and information on why HPV is a problem, including information on high and low risk types of HPV and why it causes cancers, but does not give much information about HPV and throat cancer. The information about HPV on this website was very detailed and may not be suitable for all literacy levels, especially as this is only available online where higher readability levels are required than in printed materials (Eysenbach et al., 2002). Ideally, information presented online should have higher readability levels than printed materials to account for lower reading speed, comprehension and fatigue (Redshaw, 2003). Despite the increasing prevalence of HPV-OSCC, there is a lack of appropriate and reassuring information available to help patients and their family members understand the role of HPV in their disease.

The aim of this study therefore was to develop an information booklet that is clear and accessible, would aid in the discussion of HPV-OSCC between health professionals and patients, and also provide information that patients could take home with them where it could facilitate the discussion with other family members. The booklet aimed to be clear, concise, relevant and accurate, and written in everyday language. The booklet also aimed to facilitate information about HPV-OSCC being communicated in a way which minimises any negative psychological outcomes to the patient.

9.2 Methods

The approach taken for the development of these information materials broadly followed the framework laid out in '*Simply Put: A guide for creating easy-to-understand materials*' (US Department of Health and Human Services, 2009). The steps taken are illustrated in Figure 9.1. Steps seven and eight were not carried out due to time constraints.

Steps for Developing Health Communication Materials That Are Evidence-Based and User Friendly

1. Identify intended audience and define/research the key health problems or interests
2. Engage the intended audience- determine what their needs, beliefs/values, and interests are, and their level of knowledge of the identified health topic
3. Determine key concepts and messages based on knowledge of the audience
4. Design a draft of the material
5. Pretest materials with intended audience
6. Tweak draft according to feedback from the audience
7. Publish and distribute materials
8. Evaluate the audience's satisfaction and understanding

Figure 9.1: Steps followed in development of the information materials (US Department of Health and Human Services, 2009)

9.2.1 Process of gathering information

Health Professionals: The findings from the interview study with health professionals (chapter 6) and the survey with health professionals (chapter 7) contributed to an understanding of the components and key messages most useful to include in the booklet.

Patients and Partners: The interviews conducted with patients and their partners (chapter 8) enabled an understanding of what information they had already received and an identification of their key information needs.

The key information about HPV was extracted from the themes interpreted in the qualitative analysis from the interviews with health professionals and patients. This was information from the health professionals which was interpreted as being important to communicate to patients, and from patients and their partners as being the key information they wanted to know. Recent research and best evidence to answer these questions was then searched for using large, international databases to search for guidelines, systematic reviews or published research studies. The references for these information sources were noted.

A search was also conducted for any other relevant patient material already in circulation about HPV, including information materials explaining HPV and cervical cancer. This search was looking for any materials that already gave specific information about HPV and oropharyngeal cancer. These materials were also used to develop the structure and design of the booklet. None of the materials found were suitable as they currently stood. All the evidence from the interviews, the recent literature and relevant materials was gathered together and assessed to decide what to include in the booklet. This was assessed against the questions patients wanted

answered and most frequently searched for. This information was designed to be handed to the patient following the consultation and used as a discussion tool for health professionals. The booklets could also be available on a rack in the waiting room of the clinic and the information included in the booklet could be available online.

9.2.2 Writing the content for the booklet and measures of assessment

Using the information gathered from the interviews and from the research evidence, the content of the booklet was drafted to answer frequently asked questions and also provide important summary points for health professionals. The content includes key messages from health professionals, basic information about HPV and more specific information about HPV and OSCC and signposts to other useful websites.

Once drafted, the booklet went through a series of iterations, checking drafts against the guidance from the Plain English Campaign and checking with members of my supervisory team until it seemed easy to read. The Plain English Campaign strives for everyone to have access to clear and concise information (Plain English Campaign, 2016) and since 1990 has implemented the Crystal Mark on documents which the Plain English Campaign have worked with to make as clear as possible. The Plain English Campaign provides guidelines which were used in the development of this information to ensure that the information is as clear as possible. The Flesch Readability formula was applied to the content (Flesch, 1948). The Flesch Reading Ease⁷ rates text on a 100-point scale, with higher scores representing the text being easier to understand. A score of 60-70 is interpreted as Plain English and can be understood by 13-15 year olds. The Flesch-Kincaid Grade Level⁸ test indicates at which grade level in the USA the text is suitable for. A lower score indicates a lower grade level and reading age. Microsoft Word also gives a percentage for the number of passive sentences in the text. The score is calculated by the number of passive sentences divided by the number of active sentences. The lower the score the better as this indicates more active sentences in the text. The guidance included in Lord Moser's 1999 report 'A Fresh Start' (Department for Education and Employment, 1999;

⁷ The formula for calculating the reading ease is $[206.835 - 1.015 (\text{total words}/\text{total sentences}) - 84.6 (\text{total syllables}/\text{total words})]$

⁸ The formula for calculating the grade level is $[0.39 (\text{total words}/\text{total sentences}) + 11.8 (\text{total syllables}/\text{total words}) - 15.59]$

National Health Service, 2010) was also followed throughout the development of this information. Table 9.1 outlines the guidance followed in the development of the information.

Table 9.1: Guidelines followed in the development of the information

Plain English Campaign	Lord Moser's 'A Fresh Start'
Keep your sentences short: Short sentences, in general no more than 15 to 20 words long	Using patient-friendly text - 'We' and 'you', create a sense of inclusion and trust
Prefer active verbs	Being relevant - Make sure information is relevant to and appropriate for the patient group it is aimed at
Use 'you' and 'we'	Making sure the information is consistent
Use words that are appropriate for the reader	Making sure the information is helpful
Do not be afraid to give instructions	Do not confuse people
Avoid nominalisations: an abstract noun, the name of something that is not a physical object such as a process, technique, or emotion e.g. discussion, completion	Signpost additional resources
Use lists where appropriate	Be evidence-based and up-to-date
Lowercase letters are easier to read	
Present and active tense will make text more direct and engaging - aim for 80-90% active	
Be concise	

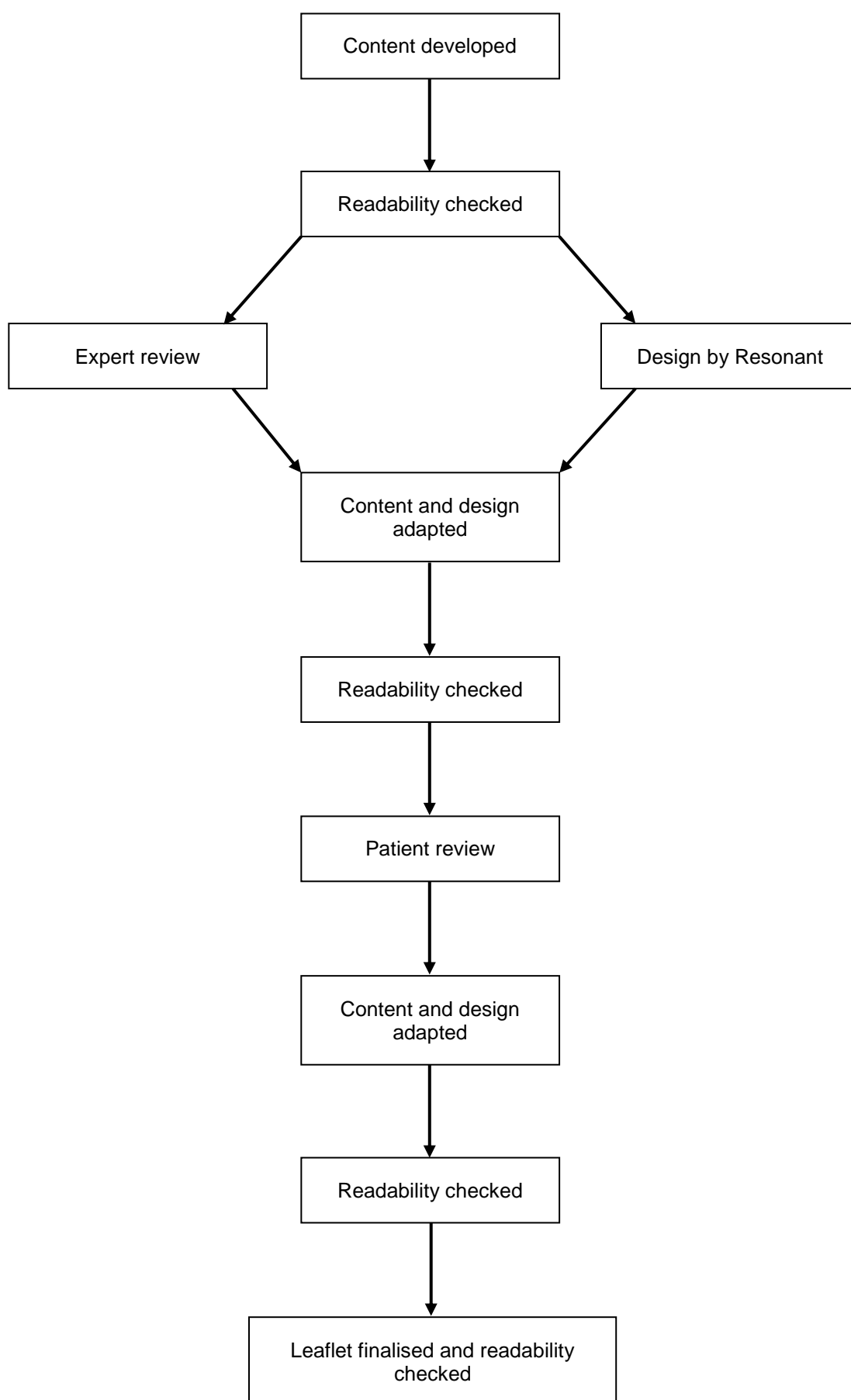


Figure 9.2: Flowchart of the stages in the development of the booklet

9.2.3 Process of developing the booklet

Resonant are a social marketing company and behavioural insight team who have been involved in the development of information materials for a number of health related projects within the Health Behaviour Research Centre at UCL and for Cancer Research UK. I met with Resonant to communicate the brief of the project (Appendix 9.1) and the content of the information was sent to Resonant at the same time as it was sent to experts for review (Figure 9.2). Resonant were responsible for the design and layout of the information booklet and took into consideration the intended audience, key information, helping patients to navigate the information, use of colour, and use of diagrams to aid in the understanding of key pieces of information. The content and design were adapted following expert review and patient review.

The information booklet went through five rounds of iterations before patient review to ensure the vocabulary was simple, re-writing sentences so they were less complex and used active sentences rather than passive. The readability score was assessed on a number of occasions as a marker for an improvement in the readability of the language (Figure 9.2). The final booklet was developed with a final iteration following the patient review.

Expert evaluation

Once my supervisory team and I were happy with the first draft, the content was sent to experts to check accuracy and that it reflected the best evidence available. This was a group of five experts who included: a field-based expert (British virologist and epithelial biologist working in HPV and cervical cancer), two HNC clinical experts (one surgeon, one speech and language therapist), a communications expert (academic working in health literacy) and an expert in psycho-oncology and healthcare communications (academic behavioural scientist). The booklet was sent with a deadline for feedback. The experts were asked to comment on:

- Their overall impressions of the booklet
- The order of the information presented
- The use of headings throughout the booklet
- If the booklet answers the questions they feel are important
- If there are any other questions that should be included
- If any of the information is unhelpful

- If the information is accurate
- If relevant, whether they would be happy going through the booklet with patients
- Whether any of the information was unnecessary
- Any other comments/changes they would like to see

Where there was disagreement about different information, I took responsibility for finding empirical evidence and made the final decision.

Is there a vaccine available to protect against HPV?

Girls aged 12 to 13 are offered the HPV vaccine free from the NHS, to protect them from cervical cancer. Girls are vaccinated at this age as this is when they will have the best immune response to the vaccine. Girls can get the vaccine on the NHS up to the age of 18. Boys can be vaccinated privately at a cost.

We don't know for certain whether the vaccine prevents throat cancer – researchers are still working on this.

The vaccine has also been approved for men under 45 who have sex with men. The vaccine will be available to them in clinics.

To find out more: www.nhs.uk/conditions/vaccinations/pages/hpvhuman-papillomavirus-vaccine.aspx

Will I get another cancer from HPV?

Throat cancers caused by HPV respond well to treatment and your chance of making a full recovery is much higher than with similar, smoking or alcohol-related cancers.

People sometimes worry they'll get another cancer caused by HPV. This is unlikely because the chance of an HPV infection leading to cancer is low.

You can help yourself stay healthy by not smoking and limiting the amount of alcohol you drink (the government recommends drinking no more than 14 units a week). You should also visit your dentist regularly so they can check that your mouth is healthy.

Things to remember about HPV

- Having HPV is a result of normal sexual behaviour. Most sexually active people will get it at some point in their lives.
- It's rare for HPV infection to turn into cancer. We don't yet know why some people get cancer and others do not.
- It's likely you got HPV at least ten years before you were diagnosed with cancer.
- Having HPV does not mean that you or your partner has been unfaithful.
- Some people get HPV from one sexual partner, but the risk of HPV increases with the number of sexual partners you have.
- HPV-related throat cancers respond better to treatment than head and neck cancers caused by smoking and drinking alcohol.

Find out more

These websites have more information you might find useful.

www.macmillan.org.uk/Cancerinformation/Cancertypes/Headneck/Typesofheadneckcancers/Oropharynx.aspx

www.cancerresearchuk.org/about-cancer/causes-of-cancer

www.throatcancerfoundation.org/hpv

Date printed:

Note

This leaflet was developed by the Health Behaviour Research Centre, University College London and Resonant agency.

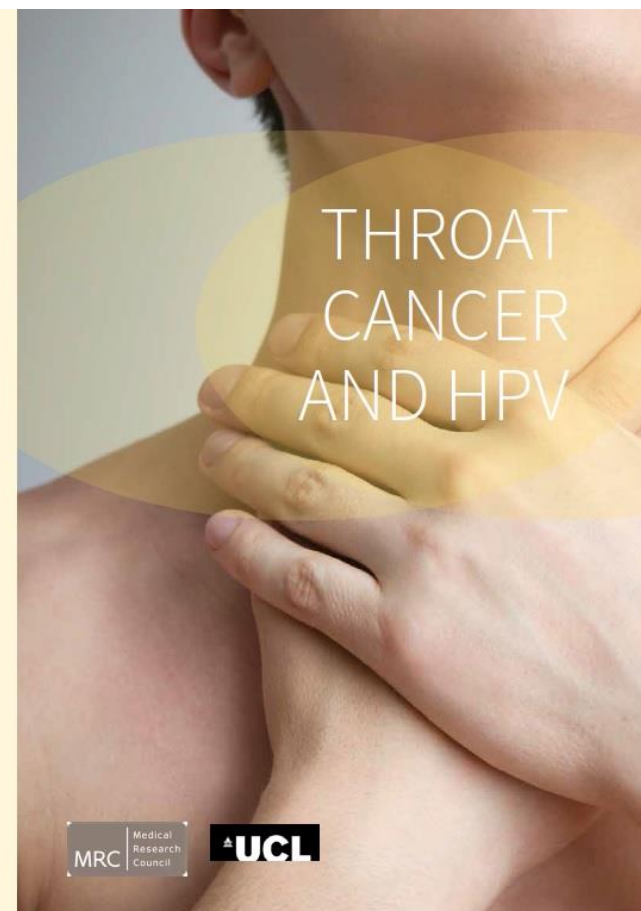


Figure 9.3: Draft 1 – Developed after receiving feedback from the experts

What is HPV?

If you've been diagnosed with cancer linked to the HPV virus, you probably want to know what the virus is, how you got it and whether you could pass it on.

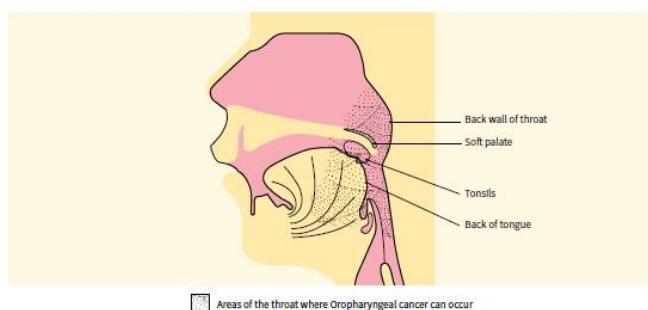
HPV is the short name for the human papillomavirus. This extremely common virus affects most people during their lifetime. It will only lead to cancer in some people – and we don't yet know why.

Remember most people get the HPV virus at some point and don't even know it. You're not responsible for your throat cancer and you don't need to make big changes to your behaviour now.

HPV-related throat cancers tend to respond better to treatment. This may provide a better outlook than similar throat cancers caused by other factors, such as smoking and drinking alcohol.

Throat cancer

In this leaflet we'll use the term throat cancer to refer to the different cancers that affect the areas of the mouth and throat shown in the diagram. Their medical name is oropharyngeal (or-o-far-an-gee-al) cancer.



Areas of the throat where Oropharyngeal cancer can occur

HPV is a very common virus

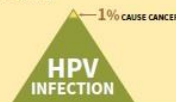
HPV is a family of common viruses that live on our skin and the moist areas of the body, such as:

- mouth & throat
- male genitals (penis, testicles)
- female genitals (vulva, vagina and cervix)
- anus and rectum

Most types of HPV do not cause cancer, but a few can. In 2006 a vaccine to stop the most common HPV infections was developed. We expect this will prevent HPV cancers in the future.

There are many types of HPV and each type has its own number. Some HPV types don't cause serious problems – these are called 'low risk' types. Others are 'high risk' and can cause cancer.

HPV-16 is the high risk type that causes almost all of the oropharyngeal cancers caused by HPV.



What types of HPV can cause cancer?

Low risk	High risk
Can cause: <ul style="list-style-type: none"> • Skin warts on your hands • Verrucas on the soles of your feet • Genital warts in your genital area and around the anus 	<ul style="list-style-type: none"> • Cause most HPV-related cancers, including throat cancer • Nearly all cases of cervical cancer • HPV-16 and HPV-18 are the two most common high risk types

How HPV can be passed on?

Eight out of ten sexually active men and women will catch an HPV virus that could cause cancer at some point in their lives.

These types of HPV infection have no obvious symptoms. So it's possible you could have had it for many years without knowing.

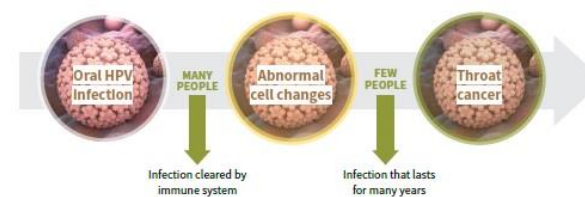
The virus is passed through skin-to-skin genital, oral and anal contact, during sexual activity.

You can get HPV from just one sexual partner, but the risk of getting HPV goes up with the number of partners a person has.

How did my HPV infection turn into cancer?

Most people who get HPV fight it off and it goes away without causing problems. We don't yet know why the virus stays in some people, but it is more likely to stay if you smoke.

But in a few cases, this doesn't happen. When the infection stays in the body it sometimes causes cells to become abnormal. Over time these abnormal cells can turn into cancer.



Do I still have HPV?

At this stage, we don't know. Three things can happen:

- HPV goes away
- HPV hides from the test but stays in the body
- HPV stays in the body and can be found with a test

Is my partner at risk of getting HPV?

Sometimes people worry that they'll pass on HPV to their loved ones, and therefore give them cancer. This isn't something you should worry about.

If you and your partner have been together for a while you will probably have passed the HPV between you already. HPV infections are very common but HPV-related cancers are rare. So the chance of your partner getting this type of cancer is very low.

HPV is passed through skin-to-skin contact, but if you have a new partner, using condoms for vaginal, anal and oral sex can reduce the risk.

Figure 9.3: Draft 1 – Developed after receiving feedback from the experts (contd.)

Patient evaluation

Following expert review, the booklet (Figure 9.3) was adapted before being tested with HNC patients to assess its ease of use, its relevance and accessibility. Five patients from my PAG were asked to rank a selection of front cover options (Figure 9.4) in order of preference and comment on the revised booklet (Figure 9.5). Three of the patients were recruited to the PAG through the online advertisement on The Throat Cancer Foundation website and two of the patients had joined the PAG following being interviewed for the study conducted in chapter 8. The patients were asked to comment on:

- Their overall impressions of the booklet
- The language used in the booklet /is it written in words they can understand
- The order of the information presented
- The use of headings throughout the booklet
- If the booklet covers the things they feel are important
- If there is any information missing that they would have liked to be included
- If any of the information is unhelpful
- Whether any of the information was unnecessary
- Any other comments/changes they would like to see

Patients were followed up with a short telephone interview to explore their feedback. Any barriers to patients' understanding of the information presented and comments were carefully considered and changes to the booklet were made to improve it. Including patients in the design of the booklet helped to ensure that the information will be read and understood.

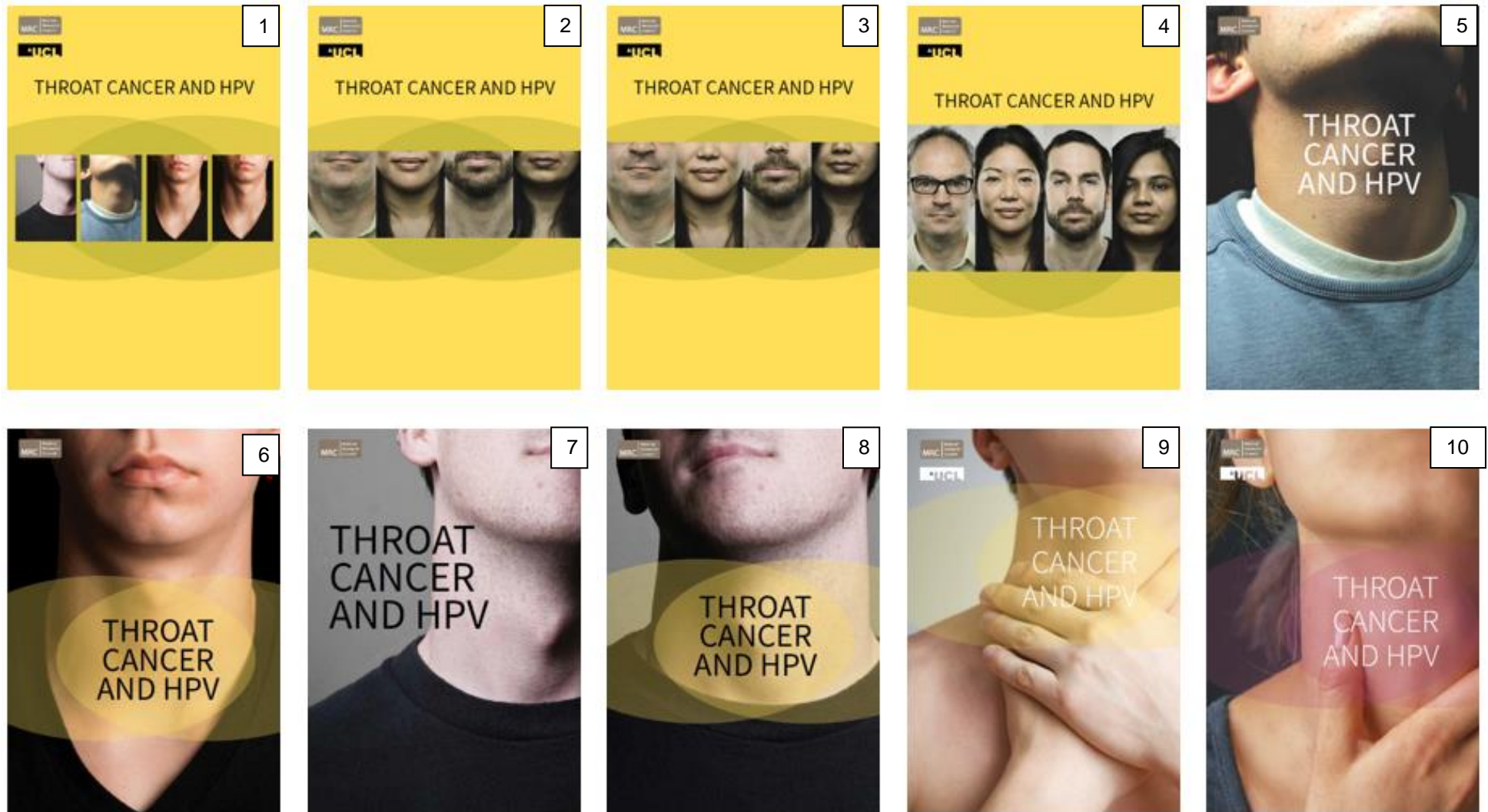


Figure 9.4: Draft 2 - Front cover options presented to patients for feedback

What is HPV?

If you've been diagnosed with throat cancer linked to the HPV virus, you probably want to know what the virus is, how you got it and whether you could pass it on.

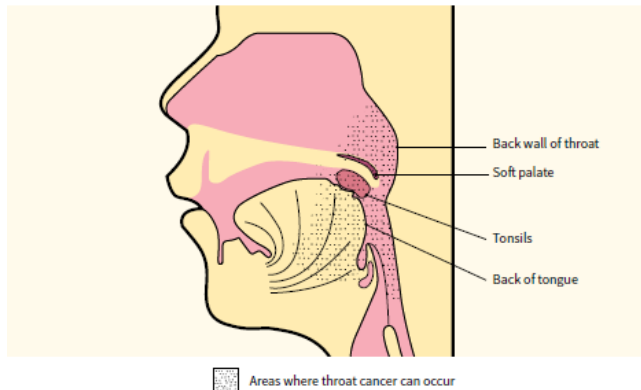
HPV is the short name for the human papillomavirus. This extremely common virus affects most people during their lifetime. It will only lead to cancer in some people – and we don't yet know why.

Remember most people get the HPV virus at some point and don't even know it. You're not responsible for your throat cancer and you don't need to make changes to your behaviour.

HPV-related throat cancers tend to respond better to treatment. This may provide a better outlook than for similar throat cancers caused by other factors, such as smoking and drinking alcohol.

Throat cancer

In this leaflet we'll use the term throat cancer to refer to the different cancers that affect the areas of the mouth and throat shown in the diagram. Their medical name is oropharyngeal (or-o-far-an-gee-al) cancer.



HPV is a very common virus

HPV is a family of common viruses that live on the skin and the moist areas of the body, such as:

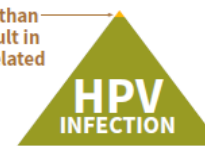
- mouth & throat
- male genitals (penis, testicles)
- female genitals (vulva, vagina and cervix)
- anus and rectum

There are many types of HPV and each type has its own number. Some HPV types don't cause serious problems – these are called 'low risk' types. Others are 'high risk' and can cause cancer.

Most types of HPV do not cause cancer, but a few can. In 2006 a vaccine to stop the most common cancer-causing HPV types was developed. We expect this will prevent HPV cancers in the future.

Most throat cancers caused by HPV come from HPV type 16.

Fewer than 1% result in HPV-related cancer



What types of HPV can cause cancer?

Low risk	High risk
Can cause: <ul style="list-style-type: none"> • Skin warts on your hands • Verrucas on the soles of your feet • Genital warts in your genital area and around the anus • Does not cause cancer 	Can cause: <ul style="list-style-type: none"> • HPV-related cancers, including throat cancer • Nearly all cases of cervical cancer • HPV-16 and HPV-18 are the two most common high risk types

How can HPV be passed on?

Eight out of ten sexually active men and women will catch an HPV virus that could cause cancer at some point in their lives.

These types of HPV infection have no obvious symptoms. So it's possible you could have had it for many years without knowing.

The virus is passed through skin-to-skin genital, oral and anal contact, during sexual activity.

You can get HPV from just one sexual partner, but the risk of getting HPV goes up with the number of partners a person has.

HPV is a very common virus

HPV is a family of common viruses that live on the skin and the moist areas of the body, such as:

- mouth & throat
- male genitals (penis, testicles)
- female genitals (vulva, vagina and cervix)
- anus and rectum

There are many types of HPV and each type has its own number. Some HPV types don't cause serious problems – these are called 'low risk' types. Others are 'high risk' and can cause cancer.

Most types of HPV do not cause cancer, but a few can. In 2006 a vaccine to stop the most common cancer-causing HPV types was developed. We expect this will prevent HPV cancers in the future.

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The virus is passed through skin-to-skin genital, oral and anal contact, during sexual activity.

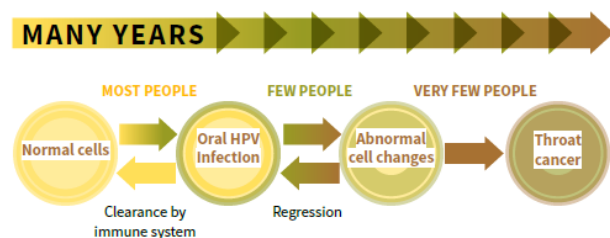
You can get HPV from just one sexual partner, but the risk of getting HPV goes up with the number of partners a person has.

Figure 9.5: Draft 2 - Booklet sent to patients for feedback

How did my HPV infection turn into cancer?

For most people who get HPV it goes away on its own without causing problems. But in a few cases, this doesn't happen. We don't yet know why the virus stays in some people, but we know it is more likely to stay if you smoke.

When the infection stays in the body it sometimes causes cells to become abnormal. Over time these abnormal cells can turn into cancer.



Do I still have HPV?

At this stage, we don't know. When you have HPV, three things can happen:

- HPV goes away
- HPV hides from the test but stays in the body
- HPV stays in the body and can be found with a test

Is my partner at risk of getting HPV?

Sometimes people worry that they'll pass on HPV to their loved ones, and therefore give them cancer. This isn't something you should worry about.

If you and your partner have been together for a while you will probably have passed the HPV between you already. HPV infections are very common but HPV-related cancers are rare. So the chance of your partner getting this type of cancer is very low.

HPV is passed through skin-to-skin contact. So we know if you have a new partner, using condoms for vaginal, anal and oral sex can reduce the risk.

Should I be vaccinated against HPV?

Girls aged 12 to 13 are offered the HPV vaccine free from the NHS, to protect them from cervical cancer. Girls are vaccinated at this age as this is when they will have the best immune response to the vaccine. Girls can get the vaccine on the NHS up to the age of 18. Boys can be vaccinated privately at a cost.

The vaccine has also been approved for men (aged under 45) who have sex with men. The vaccine will be available to them soon in sexual health clinics.

We don't know for certain whether the vaccine prevents throat cancer – researchers are still working on this.

To find out more: NHS: <http://tinyurl.com/p3r8ypd>

Will I get another cancer from HPV?

Throat cancers caused by HPV respond well to treatment and your chance of making a full recovery is much higher than with similar, smoking or alcohol-related throat cancers.

People sometimes worry they'll get another cancer caused by HPV. This is unlikely because the chance of an HPV infection leading to cancer is low.

You can help yourself stay healthy by not smoking and limiting the amount of alcohol you drink (the government recommends drinking no more than 14 units a week). You should also visit your dentist regularly so they can check that your mouth is healthy.

Things to remember about HPV

- Having HPV is a result of normal sexual behaviour. Most sexually active people will get it at some point in their lives.
- It's rare for an HPV infection to turn into cancer. We don't yet know why some people get cancer and others do not.
- It's likely you got HPV at least ten years before you were diagnosed with cancer.
- Having HPV does not mean that you or your partner has been unfaithful.
- HPV-related throat cancers respond better to treatment than throat cancers caused by smoking and drinking alcohol.

Find out more

These websites have more information you might find useful.

Macmillan: <http://goo.gl/M47Jjh>
Cancer Research UK: <http://goo.gl/96Ppcv>
Throat Cancer Foundation: <http://goo.gl/pkEhRt>

Date printed:

This leaflet was developed by the Health Behaviour Research Centre, University College London and Resonant agency.

Figure 9.5: Draft 2 - Booklet sent to patients for feedback (contd.)

9.3 Results

The information booklet was designed to provide answers to questions most frequently asked by patients in a question and answer format, and to provide a tool for health professionals to aid in communicating about HPV as a cause of OSCC to HPV-OSCC patients. Patients and health professionals were also signposted to websites which contain further information should they want to look further.

The title of the booklet was chosen to be HPV and Throat Cancer. This was because when examining the patient interviews conducted in chapter 8, this was the most commonly used term to refer to their cancer. The throat was also thought to be the place where patients are most likely to attribute their cancer to as symptoms typically start there.

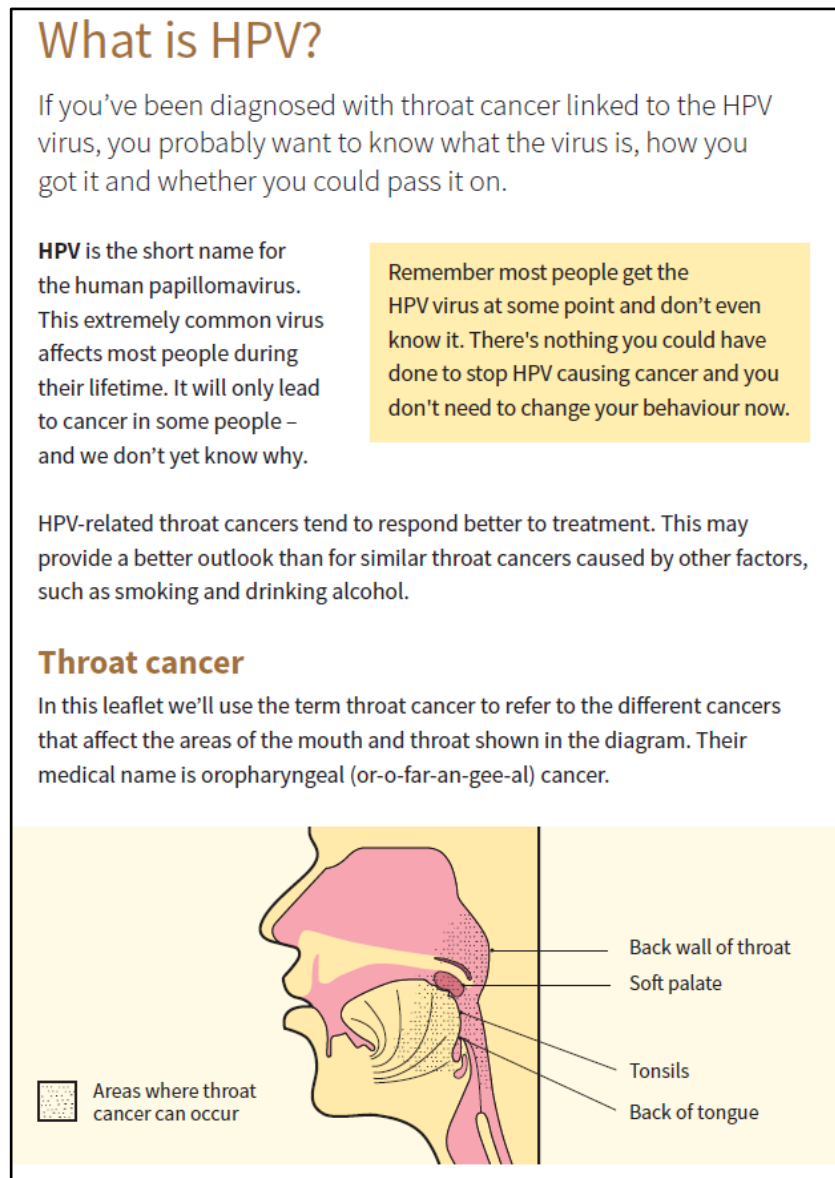


Figure 9.6: Final booklet - page 1

The first page of the booklet (Figure 9.6) gives an overview of the focus of the booklet and some basic information about HPV. As many of the patients interviewed in chapter 8 had not heard of HPV before being told their diagnosis, it was important to include an explanation about the virus and to reassure patients that this is a common virus and that in the case of throat cancer, it is more treatable. Including a diagram of the throat was also to help explain to patients where their cancer is located as they are likely to have been told by their doctor where their primary tumour was found, as was the case for the patients in chapter 8. This is also included to facilitate the discussion of HPV between health professionals and patients.

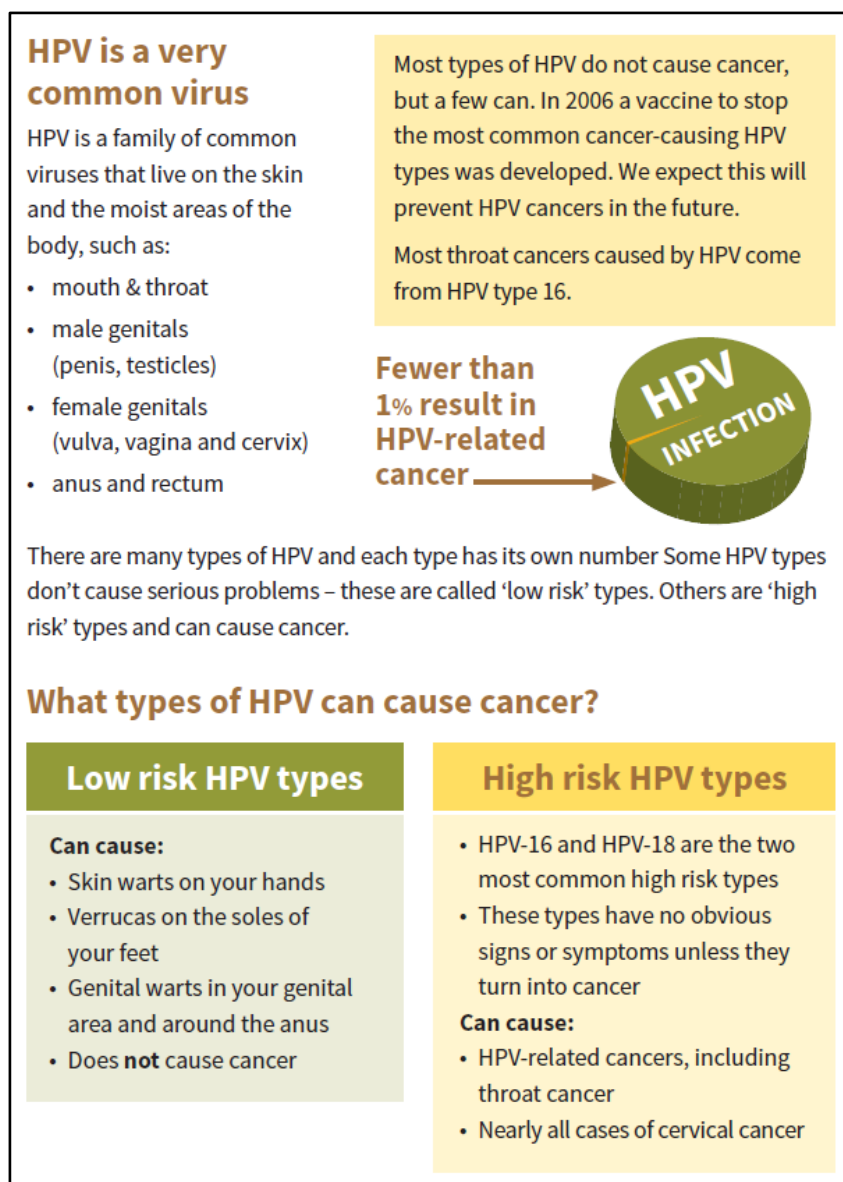


Figure 9.7: Final booklet - page 2

The second page of the booklet (Figure 9.7) includes further basic information about HPV which was included as evidence has shown basic information about HPV to be beneficial (Waller et al., 2007) and patients in chapter 8 who had been given information about the high prevalence of HPV felt reassured. Additionally, including information about the low-risk and high-risk types of HPV was important to include to explain to patients that not all types of HPV cause cancer. Including a pie chart to demonstrate that a very small percentage of those who have HPV go on to get cancer, was suggested by the health literacy expert, explaining some concepts through diagrams.

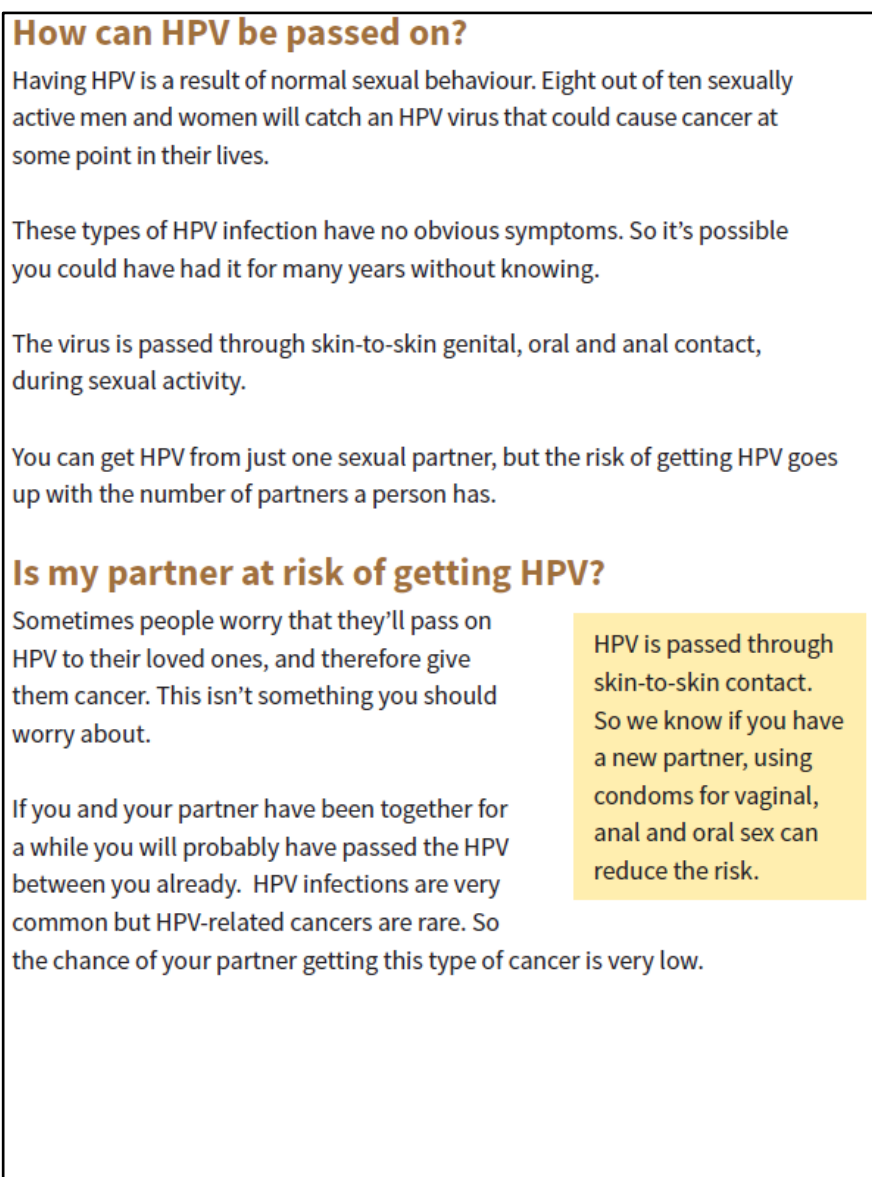


Figure 9.8: Final booklet - page 3

The third page of the booklet (Figure 9.8) begins to answer some of the specific questions patients had about HPV. How they had got HPV and whether HPV could be transmitted were common questions expressed to health professionals in chapter 6 and by patients in chapter 8. There was also a worry from patients and also from partners, as to whether they could be at heightened risk. An important message to reiterate was that HPV is a result of normal sexual behaviour as this has been found to be reassuring and was specifically mentioned in the feedback from patients. The information about partners being at increased risk is aimed at reassuring couples that HPV-related cancers are rare and so they are at low risk of getting a cancer caused by HPV. Information was also included about future partners, for patients not currently with a partner.

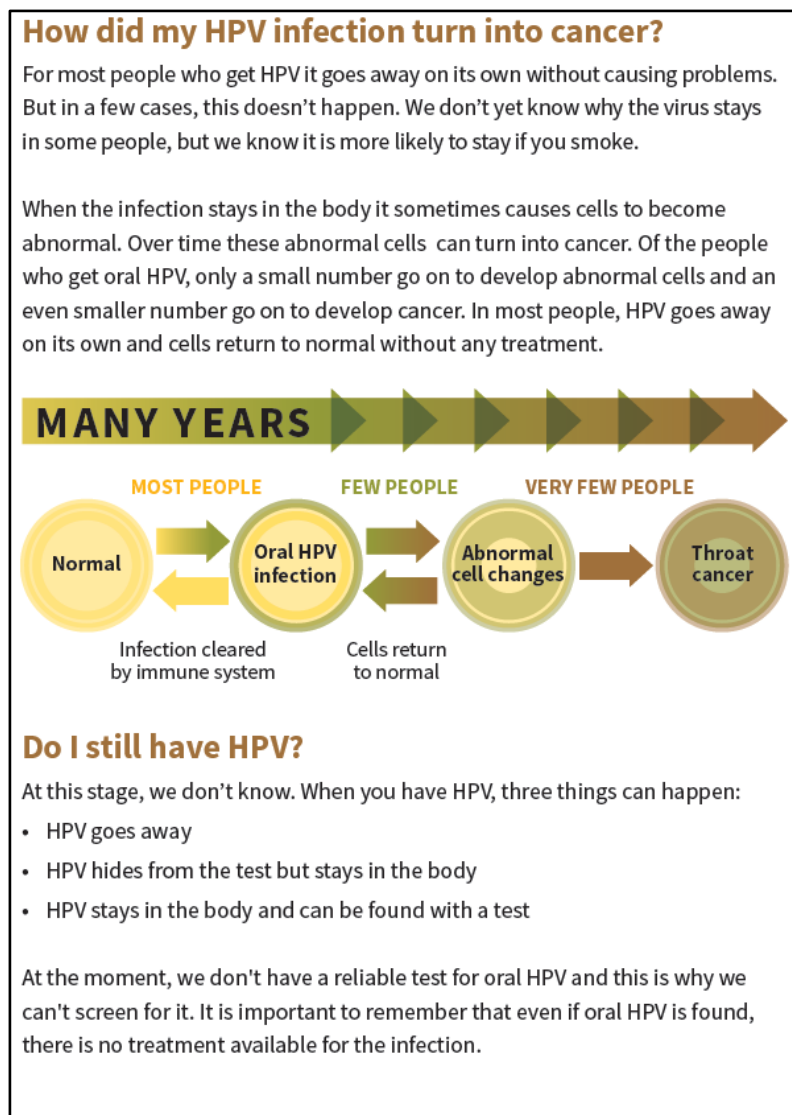


Figure 9.9: Final booklet - page 4

Page four (Figure 9.9) continues to answer questions posed by patients, progressing from how they might have got HPV, to how HPV turned into cancer. As there are still many unknowns around this question, these were acknowledged and expressed. One of the patients in chapter 8 quoted what her oncologist had told her about the progression of HPV which had really reassured her and she found it straightforward to follow. That explanation was adapted for use in answering this question. Patients also wanted to know whether they still have HPV after they have been treated for their cancer, and it was important to acknowledge that there is no clear evidence to suggest whether they have or they have not, and also that there is no reliable test available yet for oral HPV. The health literacy expert contributed to the wording of the response to 'Do I still have HPV?' to help make this as simple and straightforward as possible.

What about the HPV vaccine?

Girls aged 12 to 13 are offered the HPV vaccine free from the NHS, to protect them from cervical cancer caused by HPV. Girls are vaccinated at this age as this is when they will have the best immune response to the vaccine. Girls can get the vaccine on the NHS up to the age of 18. Boys can be vaccinated privately at a cost.

The vaccine has also been approved for men (aged under 45) who have sex with men to protect them from anal cancer caused by HPV. The vaccine will be available to them soon in sexual health clinics.

We don't know for certain whether the vaccine prevents throat cancer caused by HPV – researchers are still working on this.

We do know the vaccine won't help if you currently have an HPV infection. But it will help prevent future infections, or infections with different HPV types.

To find out more visit NHS Choices: <http://tinyurl.com/p3r8ypd>

Will I get another cancer from HPV?

Throat cancers caused by HPV respond well to treatment and your chance of making a full recovery is much higher than with similar, smoking or alcohol-related throat cancers.

People sometimes worry they'll get another cancer caused by HPV. This is unlikely because the chance of an HPV infection leading to cancer is low.

You can help yourself stay healthy by not smoking and limiting the amount of alcohol you drink (the government recommends drinking no more than 14 units a week). You should also visit your dentist regularly to check your mouth is healthy and go for your hospital follow-up appointments.

To find out more about reducing your risk of cancer visit Cancer Research UK: <http://goo.gl/96Ppcv>

Figure 9.10: Final booklet - page 5

Page 5 (Figure 9.10) of the booklet included another two questions posed by patients. The HPV vaccine was mentioned in chapter 8 by some of the patients who have children and also a couple who had chosen to pay for the vaccine privately themselves. Health professionals also said that patients asked them about the HPV vaccine. As all the information about the HPV vaccine has been conducted with cervical cancer, the evidence for the efficacy of the vaccine against oral HPV has not yet been established and it was important to say this. Patients had demonstrated relief and reassurance in chapter 8 when they were told about the positive prognosis of HPV-OSCC and general lifestyle advice was included to inform patients of other ways to help prevent cancer in the future.

Things to remember about HPV

- Having HPV is a result of normal sexual behaviour. Most sexually active people will get it at some point in their lives.
- It's rare for an HPV infection to turn into cancer. We don't yet know why some people get cancer and others do not.
- It's likely you got HPV at least ten years before you were diagnosed with cancer.
- Having HPV does not mean that you or your partner has been unfaithful.
- HPV-related throat cancers respond better to treatment than throat cancers caused by smoking and drinking alcohol.

Figure 9.11: Final booklet - page 6

The final page of the booklet (Figure 9.11) reiterated some of the key messages interpreted from the health professional interviews, to reassure patients and help minimise any negative psychological impact. This included some of the key messages from health professionals in chapter 6.

The back cover of the booklet (Figure 9.12) also included reliable and trusted websites where patients and/or their family members could look for further information.

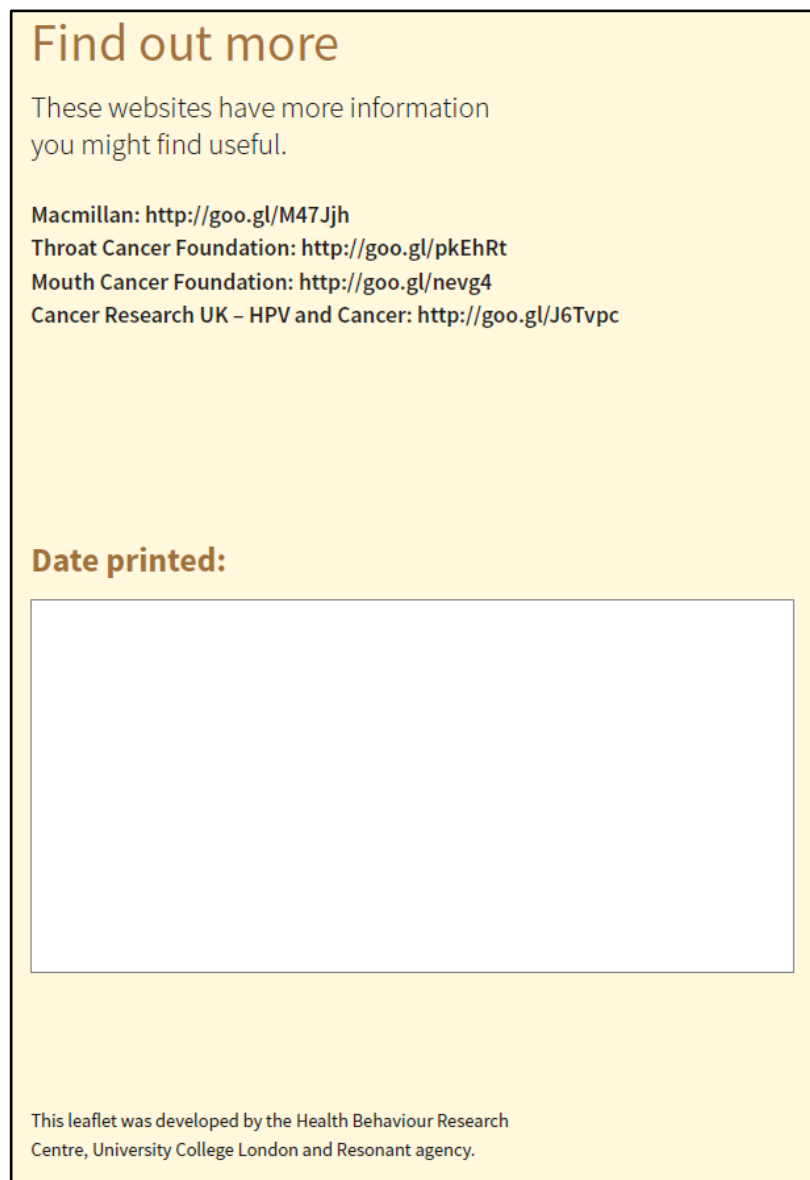


Figure 9.12: Final booklet - back cover

9.3.1 Expert review

The Flesch Reading Ease score, Flesch-Kincaid Grade Level score and percentage of passive sentences in the content sent to the experts was 71.7/100, 6.6 (ages 11-12), and 20% respectively. The lower the percentages of passive sentences the better, as this indicates more active sentences in the text. One health professional said 'it will be an extremely useful document'. Feedback from the expert review was very thorough and included advice about the language used and clarifying the accuracy of some of the information used (Appendix 9.2). For example, this one health professional commented on the section 'What is HPV?' that it could be expanded to explain that the majority of people will clear the infection and that only a very small number go on to get cancer.

'Maybe expand this to highlight that the vast majority of us will clear the infection, a small number will set up a chronic infective/inflammatory state while only a very small % of us will go on to get cancer'. (Male, health professional)

Other comments from this expert included clarifying information about the HPV vaccine, particularly around the effectiveness of being vaccinated after being infected with HPV, the approval of the vaccine for men who have sex with men (MSM) and reasons for girls being included in the national immunisation programme. The evidence behind the inclusion of information about behavioural actions such as cervical screening, condom use and attending a dentist regularly were questioned.

The health literacy expert commented on the content of the information and also the use of graphics. This expert helped simplify the language used and made suggestions of techniques to use to do this. For example, spelling oropharyngeal cancer out phonetically, 'The medical term for these cancers is oropharyngeal (or-o-far-an-gee-al) cancer'. Other specific comments from this expert included simplifying the diagram showing where oropharyngeal cancers are located, clarifying low and high-risk HPV types and including more information about the HPV vaccine, such as whether it is free and if they can get their boys vaccinated if they are willing to pay for it, and simplifying information about whether the HPV vaccine will prevent against throat cancers in the future.

Specific advice came from the speech and language therapist working with HNC patients about how patients might feel about some of the language used based on her experiences of communicating with them. An example included a comment based on the section about the prognosis being 'good news'. The speech and language therapist explained that some of her HNC cancer patients expressed the view that cancer can never feel like good news.

'I am a bit cautious about the "good news" - My PPI [Patient and Public Involvement] group think that getting cancer can never feel like good news, so being told that your cancer may respond better and therefore this is good news may be construed differently by different patients. Might be best to keep to fact'. (Female, speech and language therapist)

Further comments included moving some of information from under one heading to another heading and simplifying the diagrams included, in particular the diagram illustrating the progression of oral HPV to throat cancer.

9.3.2 Patient review

After all the amendments and improvements made conjointly between Resonant, my supervisory team and I, the Flesch Reading Ease score, Flesch-Kincaid Grade Level score and percentage of passive sentences for the draft of the booklet sent to the patients for feedback was 78.5/100, 3.9 (ages 9-10) and 7% respectively. Encouragingly all the patients were very positive about the booklet and would have liked to have received it when they were diagnosed. Some of the comments that came from patients about the content included clarifying some of the information about the vaccination, in particular whether the vaccine works only for women and MSM, and whether the vaccine prevents throat cancer. Some patients also wanted some additional explanation for the diagram demonstrating the progression of oral HPV to throat cancer to aid in their understanding (Appendix 9.3).

The front cover labelled number 4 in Figure 9.4 which shows two men and two women from different ethnic backgrounds was the most favoured for the front cover, ranked first by two patients, third by two patients and fifth by one patient. The reasons patients favoured this cover were because it had a mixture of men and women and 'because it reflected the broad spectrum of people that can and do get HPV-related cancers'. Some patients found the options with just the person's throat 'a bit creepy'. Two patients liked the covers with four people on the front, with one patient preferring those covers which focused on the throats as he said, 'personally I think the one that spoke out to me was everyone's throats, because that is the initial, that is what we're talking about'. Some patients said they did not feel that strongly about the cover.

All patients were asked for their overall impressions about the booklet and all patients were positive.

'Thanks for sending me this brochure. It is extremely good, I wish my wife and I had access to this when I was first diagnosed. I think this brochure is excellent, and will be very useful for people diagnosed with these cancers, and for their family and friends'. (Male, patient)

One of the patients commented that this would have been a useful resource to have had available to help communicate to her family that her HNC was HPV-related.

'Excellent to have a resource, I would have found this really useful at the point of diagnosis, especially to share with family as HPV-related cancer is very difficult to talk about, especially with children and older relatives. I didn't share the specific details of my cancer for exactly this reason'. (Female, patient)

The patients said it was easy to read, one particularly commenting that they liked the ‘guide on how to pronounce oropharyngeal’. The order of the information was well accepted by all patients, with just a few small suggestions about repeating one of the key messages that having HPV is a result of normal sexual behaviour. The headings were said to be useful, but one of the patients commented that one of the questions (Should I be vaccinated?) posed was not answered.

Patients were asked to express their preference between a pie chart and a pyramid depicting that less than one per cent of those who get HPV go on to get cancer. The preference was for the pie chart.

All patients believed the booklet covers the things they believe are important, but made some suggestions about additional websites that could be signposted, about considering listing the high and low-risk HPV types, more information about the vaccine (as discussed above), a more detailed explanation of what HPV is, whether they can be tested to see if they still have HPV and if there are any implications for patients’ children.

9.3.3 Examples of amendments

A printed copy of the final draft of the information booklet is appended. The Flesch Reading Ease, Flesch-Kincaid Grade Level score and percentage of passive sentences for the final information booklet were 77.3, 4.2 (ages 9-10) and 5% respectively. Resonant asked questions about the content in the beginning stages to clarify the content and become familiar with the available evidence. Table 9.2 gives some examples of changes made from paragraphs in the original content, to changes made through input from Resonant, after the expert review and what they are now following both expert and patient review. This section includes some examples of sections which were amended through an iterative process following both expert and patient feedback and explains why and how these sections were changed.

The information under the heading, ‘How did I get HPV?’ was amended following comments received from experts and input from Resonant. One expert suggested including the word ‘probably’ prior to open mouth kissing because the real risk is transmitting HPV through the tongue or oral skin on the penile skin. Another expert was also cautious as individual sexual practice is difficult to quantify in terms of risk. The heading of the section was amended after

review by my supervisory panel and I to 'How can HPV be passed on?' After the feedback from patients just one sentence was added. One patient commented that they would like the prevalence of HPV to be reiterated and so the sentence 'Having HPV is a result of normal sexual behaviour' was added to the beginning of the paragraph.

The second example given is under the heading, 'Is my partner at risk of getting HPV?' At first this contained information about cervical screening being important for the patients' partner, but this was removed after comments that it was not relevant in this context. The content was amended through iterations between Resonant, myself and my supervisory team aiming to simplify the vocabulary and make the sentence less complex. When designed by Resonant, the paragraph relating to condom use with new partners was highlighted in a box as this is a behaviour patients can adopt to help prevent transmission of HPV.

The final example in the section, 'Should I be vaccinated against HPV?' went through a number of iterations. A key comment from one of the patients was that the question had not been answered and so the title of the heading was changed so that some background about the vaccine could be explained, and to also acknowledge that there are currently no clear recommendations. The information in this section was also clarified to include a sentence about the effectiveness of the vaccine on current HPV infections, future infections and infections with different HPV types.

Table 9.2: Examples of original paragraphs and what they were amended to

Original paragraph	Paragraph after expert feedback	Final paragraph (following expert and patient feedback)
<p>How did I get HPV?</p> <p>HPV is passed through skin-to-skin contact with someone who has the virus. This can include genital, oral and anal contact. Open mouth kissing and oral sex can be risk factors for oral HPV. Risk of getting HPV goes up with the number of sexual partners a person has but you can get it from just one partner.</p>	<p>How HPV can be passed on?</p> <p>Eight out of ten sexually active men and women will catch an HPV virus that could cause cancer at some point in their lives.</p> <p>These types of HPV infection have no obvious symptoms. So it's possible you could have had it for many years without knowing.</p> <p>The virus is passed through skin-to-skin genital, oral and anal contact, during sexual activity.</p> <p>You can get HPV from just one sexual partner, but the risk of getting HPV goes up with the number of partners a person has.</p>	<p>How can HPV be passed on?</p> <p>Having HPV is a result of normal sexual behaviour. Eight out of ten sexually active men and women will catch an HPV virus that could cause cancer at some point in their lives.</p> <p>These types of HPV infection have no obvious symptoms. So it's possible you could have had it for many years without knowing.</p> <p>The virus is passed through skin-to-skin genital, oral and anal contact, during sexual activity.</p> <p>You can get HPV from just one sexual partner, but the risk of getting HPV goes up with the number of partners a person has.</p>

Table 9.2: Examples of original paragraphs and what they were amended to (contd.)

<p>Is my partner at risk of HPV?</p> <p>If you have been together for several years it is likely that you and your partner have passed HPV between you lots of times. HPV infections are very common but HPV-related cancers are not common. So the chance of your partner getting an HPV-related cancer is low.</p> <p>It is important that all women aged 25-64 years go for cervical screening when invited to reduce the risk of cervical cancer.</p> <p>Using condoms for all sexual behaviours with future partners can reduce the risk of HPV being passed on but does not provide complete protection. HPV is passed through skin-to-skin contact.</p>	<p>Is my partner at risk of getting HPV?</p> <p>Sometimes people worry that they'll pass on HPV to their loved ones, and therefore give them cancer. This isn't something you should worry about.</p> <p>If you and your partner have been together for a while you will probably have passed the HPV between you already. HPV infections are very common but HPV-related cancers are rare. So the chance of your partner getting this type of cancer is very low.</p> <p>HPV is passed through skin-to-skin contact, but if you have a new partner, using condoms for vaginal, anal and oral sex can reduce the risk.</p>	<p>Is my partner at risk of getting HPV?</p> <p>Sometimes people worry that they'll pass on HPV to their loved ones, and therefore give them cancer. This isn't something you should worry about.</p> <p>If you and your partner have been together for a while you will probably have passed the HPV between you already. HPV infections are very common but HPV-related cancers are rare. So the chance of your partner getting this type of cancer is very low.</p> <p>HPV is passed through skin-to-skin contact. So we know if you have a new partner, using condoms for vaginal, anal and oral sex can reduce the risk.</p>
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Table 9.2: Examples of original paragraphs and what they were amended to (contd.)

<p>Should I be vaccinated against HPV?</p> <p>We still do not know if the HPV vaccine stops throat cancer. Researchers are working to find out if the HPV vaccine might also work for throat cancers as it does for cervical cancers. We do know that the HPV vaccine can stop HPV infection from staying for a long time in the mouth and throat.</p> <p>As a large number of HPV-related throat cancers are caused by HPV-16, researchers are hopeful that vaccinating children now will protect them against HPV-related throat cancers in the future.</p>	<p>Is there a vaccine available to protect against HPV?</p> <p>Girls aged 12 to 13 are offered the HPV vaccine free from the NHS, to protect them from cervical cancer. Girls are vaccinated at this age as this is when they will have the best immune response to the vaccine. Girls can get the vaccine on the NHS up to the age of 18. Boys can be vaccinated privately at a cost.</p> <p>We don't know for certain whether the vaccine prevents throat cancer – researchers are still working on this.</p> <p>The vaccine has also been approved for men under 45 who have sex with men. The vaccine will be available to them in clinics.</p> <p>To find out more: www.nhs.uk/conditions/vaccinations/pages/hpvhuman-papillomavirus-vaccine.aspx</p>	<p>What about the HPV vaccine?</p> <p>Girls aged 12 to 13 are offered the HPV vaccine free from the NHS, to protect them from cervical cancer caused by HPV. Girls are vaccinated at this age as this is when they will have the best immune response to the vaccine. Girls can get the vaccine on the NHS up to the age of 18. Boys can be vaccinated privately at a cost.</p> <p>The vaccine has also been approved for men (aged under 45) who have sex with men to protect them from anal cancer caused by HPV. The vaccine will be available to them soon in sexual health clinics.</p> <p>We don't know for certain whether the vaccine prevents throat cancer caused by HPV – researchers are still working on this.</p> <p>We do know the vaccine won't help if you currently have an HPV infection. But it will help prevent future infections, or infections with different HPV types.</p> <p>To find out more visit NHS Choices: http://tinyurl.com/p3r8ypd</p>
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9.4 Discussion

The objective of this study was to design an information booklet which provides answers to questions HPV-OSCC patients frequently ask or think about, as well as to facilitate discussion between patients and health professionals. The booklet includes responses to frequently asked questions and includes basic information about HPV, its sexually transmitted nature and emphasises its high prevalence, as previous research has shown these messages can lower feelings of anxiety, shame and stigma (McCaffery et al., 2006; Waller et al., 2007). This booklet adds to the existing literature already available to patients as it is up-to-date with the latest evidence and provides a resource which can be used by health professionals to ensure messages communicated to patients about HPV and HNC are consistent. It is not unusual for patients to seek the same information from a range of professionals involved in their care and so it is vital that consistent information is provided no matter who patients speak to (Catt et al., 2005).

The Flesch Reading Ease score was 77.3 and the Flesch-Kincaid Grade Level score was 4.2, illustrating a high score which indicates ease of understanding and the grade level to be that of a 4th grader in the USA, which is ages 9-10 years old. This demonstrates that the information booklet should be accessible for all levels of health literacy, as the average reading age in the UK is 9 years of age (See A Voice, 2010). The percentage of passive sentences was 5%, adhering to and exceeding the Plain English Campaign guidelines of aiming for 80-90% of sentences being active (Plain English Campaign, 2016).

Comments provided by both experts and patients were valuable to the development of the booklet and the booklet was generally well received. All patients would have liked to have received this booklet when they were diagnosed and could use this booklet to facilitate the discussion about HPV and their cancer with their family. Patients particularly liked the guide on how to pronounce 'oropharyngeal', which to the best of my knowledge, has not been used in previous literature for this patient group. Patients commented on the language used in the booklet being easy to read and the use of headings in the design of the booklet being helpful to signpost to specific sections. As good information is also important for patients' families, this booklet could also prove to be effective and useful for them too.

It is important to involve patients in the development of information booklets such as this to assess their understanding of the content and to amend the content based on their feedback (Rudd, Kaphingst, Colton, Gregoire, & Hyde, 2004), and it is becoming increasingly common to do so with the introduction of a clear NHS policy directive (Department of Health, 1999). As there has been a significant increase in the use of the internet in the search for health-related information (Office of National Statistics., 2015), it is also important that this information booklet is made available online.

Through the development of the information booklet, it was apparent that there are still areas of the literature where there are not yet definitive answers. The literature about whether oral HPV can be transmitted through open mouth kissing is still hesitant (D'Souza et al., 2009; Pickard et al., 2012). There are also uncertainties about whether HPV remains in patients after they have been treated for their HPV-OSCC (Agrawal et al., 2008; Frakes et al., 2016; Rettig et al., 2015), and there is still a need for a reliable test for oral HPV (see section 1.2.2). The literature about whether the HPV vaccine prevents HPV-OSCC is also uncertain (see section 1.4), but the HPV vaccine has now been shown to prevent future infections or infections with different types of HPV if you have contracted and cleared HPV previously (Joura et al., 2012). It is also not possible to say for certain if a patient will not get another cancer caused by HPV.

It is also important to be aware that there is increasing recognition that each individual is different and there may be a need for information to be tailored to the unique needs of individuals, which may be something which becomes more commonplace in the future (Colledge et al., 2008; Kreuter, Strecher, & Glassman, 1999). Providing alternative formats of information has been shown to improve knowledge, user-satisfaction and health behaviour (Berkman et al., 2004). Tailored information in HNC patients has also been shown to lower levels of anxiety and depression (D'Souza et al., 2013). Tailoring the information in the booklet to alternative mediums of accessibility and to different demographics, may be something to consider for this booklet in the future.

Prior to this information being used within HNC clinics in the NHS, a formal evaluation with patients and health professionals would be optimal. An evaluation with patients would include testing the readability and comprehensibility of the booklet through cognitive interviews and assessing the acceptability of the information booklet. An evaluation with health professionals

would involve multidisciplinary team members piloting the information materials with HPV-OSCC patients at a number of NHS sites for a short period (e.g. three months) with the aim of understanding how the booklet could be used in practice and how feasible it is to use in practice. Once the evaluation is complete, if shown to be comprehensible and acceptable to patients, and feasible to implement in practice, this booklet could be used across the NHS.

9.5 Strengths and Limitations

To my knowledge, this is the most up-to-date, evidence-based information booklet available for patients diagnosed with HPV-OSCC. This resource is valuable for both patients and health professionals, as some health professionals lack the confidence to discuss HPV because of their limited knowledge (see chapters 6 and 7). The development of the information was strengthened by the inclusion of both experts and patients in the development process. Involving experts in the early stages ensured that the information included in the booklet was accurate and they also provided some useful insights into how patients might respond to certain pieces of information. The inclusion of the patients for user-testing enabled the information to be tested for its ease of understanding and also for the design of the booklet to be commented on. As the booklet was well received, this provides some confidence that the booklet will be a useful addition to HNC clinics.

It is important to not place too much emphasis on the readability scores of the booklet as readability scores are not designed to take into account the design and layout of the information and does not indicate comprehension. There is the possibility of social desirability bias in that the patients included in the user-testing of the booklet were less likely to criticise the booklet as they knew I developed it. The booklet needs to be evaluated formally with a larger sample size of patients and the comprehension of the booklet assessed, but this was not possible for the current study due to time constraints. According to Mayberry and Mayberry, an evaluation of patient information must comprise tests of readability, comprehensibility and the long-term effects of written materials (Mayberry & Mayberry, 1996). The booklet would also benefit from being evaluated for its feasibility of use in HNC clinics, by piloting its use in a number of clinics and getting feedback from the health professionals in these clinics. It is also important for this information to be made available online, given that a large number of people now look for health information online.

There are still some areas of uncertainty with HPV-OSCC and further research is needed. The information will need to be reviewed regularly and updated if new evidence has emerged that needs to be included or changed.

9.6 Conclusion

The feedback from experts and patients suggests that this information booklet will be well received by patients and a useful resource for health professionals. The development of this information booklet for HPV-OSCC patients and health professionals demonstrates where there are still gaps in our knowledge and so will need updating and reviewing. This resource also has the potential to help minimise any negative psychological consequences in patients and may increase health professionals' confidence to discuss HPV and encourage more health professionals to discuss HPV.

CHAPTER 10. GENERAL DISCUSSION AND CONCLUSIONS

10.1 Initial aims

A wealth of research has been undertaken around the psychosocial impact of being diagnosed with head and neck cancer (HNC) associated with the well known causes of tobacco and alcohol. With the incidence of HNC increasing due to the rise in those diagnosed with HPV as a causal factor, it was important to investigate the psychosocial impact of this subgroup of HNC patients and whether this was amplified with the additional dimension of HPV.

My thesis was based on eight research questions, which were addressed in five research studies, with my final study accumulating the findings from all previous chapters to produce an information booklet. Study 1 was a systematic review assessing the current literature measuring the psychological impact of an HPV diagnosis in the context of HNC in studies with patients (n=10 studies) and current knowledge of the link between HPV and HNC across a range of sample populations (n=41 studies). Study 2 was a content analysis examining media coverage in the UK of the link between HPV and HNC (n=112 articles). Study 3 was a qualitative study which purposively sampled health professionals from a range of disciplines who work with HNC patients (n=15) to explore their experiences of, and attitudes towards discussing HPV. Study 4 was an extension of study 3, developing a survey for dissemination among different health professional groups working with HPV-OSCC patients (n=260) to explore their knowledge of HPV, their experiences of and attitudes to discussing HPV with their patients. Study 5 was a qualitative study with patients diagnosed with HPV-OSCC (n=20) and with some of these patients' partners (n=12) to explore their experiences around the diagnosis of HPV-OSCC. Study 6 involved the development of an information booklet for use as a discussion tool between health professionals and patients, using evidence-based research and the other studies from my thesis towards its development. The following section summarises the findings of these eight research questions along with the implications for this field of research.

10.2 Summary of main findings and their implications

10.2.1 What is the psychological impact of an HPV diagnosis in the context of head and neck cancer according to the existing literature?

Study 1 which is presented in chapter 4, is the first systematic examination of the existing literature about the psychosocial impact of HPV diagnosis in the context of HNC. Study 1 followed the PRISMA guidelines for conducting a systematic review and found 10 papers from the existing literature examining the psychosocial impact of HPV-related HNC. The outcome measured most frequently in these studies was quality of life (QOL), albeit using a number of different QOL scales. These results demonstrated QOL in HPV-positive patients was reduced from diagnosis and throughout treatment, supporting previous research with HNC patients (Morton, 2003). Comparing QOL between HPV-positive patients and HPV-negative patients, the differences between the two patient groups were inconclusive, with HPV-positive patients having greater QOL at some time points and HPV-negative patients having greater QOL at other time points, although these differences were not always significant. There were also no significant differences in levels of anxiety or depression found in HPV-positive or HPV-negative patients, finding levels of anxiety and depression in both patient groups to be lower than in previous studies with non-HPV patients (e.g. Hassanein et al., 2005; Hutton & Williams, 2001). HPV-positive patients demonstrated moderate levels of distress, but encouragingly, low levels of self-blame. The one qualitative study with a small number of HPV-positive HNC survivors found 3/10 to express feelings of stigma or shame associated with their diagnosis. These patients also expressed optimism and relief after being informed of the better prognosis associated with HPV-positive HNC.

The findings from study 1 suggest that currently we know little about the psychosocial impact of HPV-related HNC and that the field is in relative infancy. Only one small qualitative study had been conducted, suggesting the need for further qualitative work to enable the experiences of HPV-OSCC patients to be explored in depth and to develop a greater understanding of the psychosocial impact in this HNC subgroup. This sets the scene for my thesis and demonstrates that there is therefore a need for studies to investigate the psychosocial impact of a diagnosis of HPV-related HNC further. The implications of a diagnosis of HPV-related HNC are currently uncertain and it is important to establish so that patients can be offered appropriate support or

resources. Using a standardised measure with all patients to assess psychological variables of anxiety, depression and QOL would be useful to enable firm conclusions to be drawn in the future.

10.2.2 What is known about HPV-related head and neck cancer in different population groups according to the existing literature?

The systematic review in chapter 4 (study 1) also searched the existing literature for research studies examining knowledge of the relationship between HPV and HNC. The systematic review found 41 studies examining knowledge of HPV as a cause of, or a risk factor for HNC. These studies consisted of samples from a number of different populations, across 10 different countries. Over half of these studies were conducted in the USA and none conducted in the UK, so it is not possible to draw any conclusions on knowledge of the relationship between HPV and HNC in the UK. Some of the samples included in these studies were in the medical profession; some being oral health providers, head and neck surgeons, healthcare professionals and some were in-training medical or dental students. These samples had the greatest knowledge of the relationship between HPV and HNC, with one study finding 88% of dentists and another study finding 84% of dental students were aware of HPV as a risk factor for oral cancer, which could be suggestive of this information now being included in their training. Knowledge in samples of the general population was found to be as low as 1% and no higher than 44%, with the lowest level similar to that found for knowledge of HPV as a risk factor for cervical cancer (Waller, McCaffery, & Wardle, 2004). The samples of the general population varied, with the lowest awareness being found in an online panel and the highest in gay and bisexual samples of the population. The huge variation in knowledge across samples of the general population may partly be explained by the variation in how the question was asked. The sample with the lowest awareness were asked about the most common risk factors of mouth and throat cancer, and only 4.8% of this sample also selected alcohol and 54.5% selected smoking (Luryi et al., 2014), suggesting awareness of all risk factors was low.

The results from this systematic review show there are wide disparities in knowledge that HPV can cause HNC, but it is promising that knowledge is high in health professionals, as chapter 7 (study 4) found confidence of discussing HPV to be associated with knowledge. Knowledge of the relationship between HPV and HNC is also important in clinical practice so that health

professionals do not dismiss any potential symptoms of HNC due to the demographic of the patient (Dahlstrom et al., 2013; Gillison et al., 2000). These results also have implications for public health campaigns and oral cancer awareness, giving an indication as to where knowledge is the lowest and could be targeted by these campaigns. As with HPV in cervical cancer, it is important for there to be a greater awareness of the role that HPV can play in HNC, with the hope that the more widely this is known, the less stigma will be attached to HPV, with people understanding that this is a widespread infection in those who are sexually active. This would also then have implications for patients diagnosed with HPV-related HNC as they would have a greater understanding of their diagnosis and this could help alleviate any potential negative psychosocial outcomes. Awareness of HPV as a cause of HNC could also have implications for any future oral cancer screening programmes, as if the general population are aware that they could be at risk then this could influence the uptake to these initiatives.

10.2.3 How frequently has the relationship between HPV and HNC received coverage in the British media?

The disclosure of Michael Douglas that his throat cancer was caused by HPV was timely for my PhD, occurring a few months prior to the start of my PhD. It was therefore deemed pertinent to examine what information about HPV and HNC was covered by the media, to assess what information members of the general public may have received about the relationship between HPV and HNC. The media has been found to report on a number of celebrity diagnoses of cancer, as these engage the public (Hilton et al., 2010) and there is the opportunity to educate the public. The publication search of media articles in the UK conducted in chapter 5 (study 2) revealed 265 articles that had reported on the relationship between HPV and HNC from 2001 until the date the search was conducted in August 2014. More articles were found to report on the relationship between HPV and HNC in June 2013, following Michael Douglas' interview about his throat cancer being caused by HPV. On average, there were less than two articles a month published which mentioned the relationship between HPV and HNC, showing that very little information has been presented in the media.

10.2.4 What information is included in media articles covering the relationship between HPV and HNC?

Chapter 5 (study 2) also examined the content of 112 of the articles. The sexual nature of the link between HPV and HNC was sometimes emphasised in the headlines of the articles, immediately opening up the potential for this to be sensationalised or stigmatised. Some articles suggested that this disclosure by Michael Douglas has raised awareness that HPV can cause HNC and that by mentioning oral sex, this was opening up the lines of communication for a sexual behaviour that has in the past been 'taboo'. Oral sex was mentioned in three quarters of the articles and specifically the term cunnilingus. HPV was also mentioned and described as a sexually transmitted disease and linked as a cause of HNC. Mentioning oral sex led some of the articles to suggest that oral sex might be riskier for men than for women and that also an increase in oral sex was linked to the sexual revolution of the 1960's, with this resulting in greater prevalence in oral HPV and consequently throat cancer. Although there is evidence that it may be the case that performing oral sex on a woman may result in a higher level of oral HPV exposure due to higher viral load in the female genital mucosa than in men (Fakhry et al., 2013; Pytynia et al., 2014), there is a need to decide upon the important messages which should be conveyed to the public. A few articles placed particular emphasis on the riskiness of oral sex, suggesting that it should be off the agenda and that it is life-threatening. Oral sex has been reported as becoming more commonplace and it should be framed as 'normal sexual behaviour', as most people in the UK reported having had oral sexual contact within the last year (Mercer et al., 2013).

In terms of the health information presented in these articles, just over half gave statistics about the increasing incidence of HPV and HNC and just over half also linked HPV back to being a cause of cervical cancer. Articles did fail however, to communicate the high prevalence of HPV and how common it is, with just 11% of articles giving the information that 8 out of 10 sexually active people will contract HPV. This lack of basic information about HPV was also found in media coverage about cervical cancer and HPV in relation to Jade Goody (Hilton & Hunt, 2010), a reality television personality who was publically diagnosed with terminal cervical cancer and died aged 27. The better prognosis and survival rates of patients diagnosed with HPV-related HNC was also only communicated in 16% of the articles. Articles also covered some of the campaigns about vaccinating boys against HPV and recognised that should this happen, the

vaccine would have to be re-marketed as currently it is known more often as the cervical cancer vaccine, due to it being developed primarily to prevent cervical cancer in girls. The media could be utilised to help re-market the vaccine, as when the HPV vaccination was first introduced, it attracted a lot of media attention (Forster et al., 2010).

This study demonstrates what information the media convey about the link between HPV and HNC and has advanced our understanding of some of the information that the general public have received about the link between HPV and HNC. As one of the themes interpreted from the data was the riskiness of oral sex, this suggests that the media coverage of HPV and HNC may be sensationalised or stigmatising, whereas it could be normalising the behaviour based on data showing oral sex is commonplace in the UK (Mercer et al., 2013). This could have implications for practice and the psychological health of patients diagnosed with HPV and HNC, as this could affect others people's reactions towards them and it could also affect their own feelings about themselves. This study also gives us some indication as to what information patients may have already seen when they are diagnosed with HPV-OSCC, which could provide a baseline on which to build discussions between health professionals and their patients and prepare health professionals for some of the information they may be asked questions on. The lack of basic information about HPV and its prevalence in the population, which has been shown to be important information to help alleviate anxiety and stigma (Waller et al., 2007) needs to be addressed in any future publications reporting on the link between HPV and HNC. As events such as celebrity cancer diagnoses have been shown to create a substantial amount of news coverage, this would be the most effective time to include reassuring and normalising information about HPV. The media could also use this as an opportunity to educate the public about the signs and symptoms for HNC and recommendations about what to do upon finding a symptom. It is also imperative that these messages are broadcast across broadsheet, middle-market and tabloid newspapers to minimise inequalities and consequently health outcomes.

10.2.5 What are the experiences and views of health professionals in the UK about discussing HPV with HPV-OSCC patients and how do these differ across different health professional groups?

Interviewing health professionals caring for patients with HPV-OSCC allowed me to explore their experiences and views about discussing HPV in depth. All the health professionals

interviewed in chapter 6 (study 3) regarded the role of HPV in OSCC to be an important issue and that the increasing incidence was a concern. The distinctive demographic of these patients, particularly that they are a younger group of patients, has clinical implications. These patients will have to live longer with the after-effects of their treatment and due to many of them still being actively employed, there is a greater demand for expedited rehabilitation. Regarding health professionals' attitudes towards discussing HPV, these were mixed. Some health professionals believed that it is important to discuss HPV with their OSCC patients, whereas others thought there was no clinical relevance to discussing HPV. Chapter 7 (study 4) found that specialist nurses had less negative attitudes towards discussing HPV than surgeons, speech and language therapists and the group of 'other' health professionals, which may indicate that specialist nurses feel strongly that patients should be told about their diagnosis of HPV. Chapter 6 (study 3) found one health professional suggested that patients are not concerned about the cause of their cancer, but when asked to 260 health professionals in chapter 7 (study 4), 75% strongly disagreed or disagreed with the item 'My patients are not concerned about the cause of their cancer'. The difference suggested in chapter 6 (study 3) that surgeons are less likely to discuss HPV than oncologists was not supported in chapter 7 (study 4), where there were no significant differences between surgeons and oncologists on any of the factors reflecting attitudes and beliefs about discussing HPV.

Limitations of knowledge about HPV and discomfort in talking about sexual health matters, which they are not used to doing, were two main concerns expressed by health professionals in chapter 6 (study 3) and these were also supported by findings in chapter 7 (study 4).

Knowledge has been shown previously to be an important determinant in health professionals' discussions of the HPV vaccination (Holder et al., 2013) and recommendations of the HPV vaccination have been influenced by health professionals' comfort in discussing the sexual nature of HPV (Allison et al., 2013; Bynum et al., 2014; Daley et al., 2010; McCave, 2010).

Although knowledge of HPV was found to be quite high among all health professional groups in chapter 7 (study 4), specialist nurses were those who expressed the greatest comfort in talking to their patients about sexual health matters, but were not those with the greatest knowledge of HPV. It was also a greater proportion of specialist nurses and speech and language therapists who agreed that having booklets to pass onto patients would help them to discuss HPV with them, more so than surgeons, oncologists and the 'other' health professional group. It was also

these two health professional groups who agreed that attending further training would facilitate them discussing HPV with patients. These limitations of knowledge were associated with a lack of confidence to discuss HPV with patients and also a lack of willingness to do so, indicating that simply by increasing health professionals' knowledge, this could result in an increase in confidence and a willingness to discuss HPV. As shown in chapter 7 (study 4), these results could be interpreted using the Capability Opportunity Motivation-Behaviour (COM-B) model (Michie et al., 2011), which asserts that individuals must have the capability, motivation and opportunity for behaviour change to occur. Developed as a model of behaviour which is purposefully broad that it can be applied to any behaviour, in the context of these results, the behaviour change is health professionals discussing HPV with patients. Regarding the limitations to health professionals' knowledge, it is also important to recognise that there are still a number of uncertainties around HPV and HNC and some of the questions patients ask may still be unanswerable. Health professionals recognise that they may not have all the answers and that they need more information.

Key messages to normalise HPV and reduce its psychological impact were interpreted from the health professional interviews in chapter 6 (study 3) as explaining the high prevalence of HPV, that HPV is a result of normal sexual behaviour, that they do not need to change their behaviour, that HPV has a positive prognosis and referring to HPV in the context of cervical cancer and the HPV vaccination. These key messages have also been reported in an overview paper (Evans & Powell, 2014). Communicating the message that HPV is highly prevalent has been found in previous research to be associated with lower levels of anxiety, shame and stigma (Waller et al., 2007) and is reassuring (Baxi et al., 2012; McCaffery & Irwig, 2005; Waller et al., 2005). Health professionals could also influence patients' cognitive representations of their HPV-OSCC through the five dimensions of the CSM and this could also help in developing guidance around discussing the key messages found in chapter 6 (study 3). The identity of the illness and the cause are determined when patients are told they have HPV-OSCC, and the timeline, curability and controllability dimensions are influenced by the better prognosis of HPV-OSCC. In terms of consequences, this may include longer survivorship in younger patients and an impact on sexual relationships.

In terms of experience of health professionals, as they had been seeing more and more cases of HPV-OSCC, health professionals reported that they had begun to learn what is relevant and

helpful to tell patients. Confidence was also associated with experience of discussing HPV, found in both the findings in chapter 6 (study 3) and in chapter 7 (study 4). In chapter 6 (study 3) health professionals had described their efforts to find out more information about HPV and this resulted in them feeling more confident about discussing HPV and being more open about those discussions. Chapter 7 (study 4) presented results that showed associations between years practising in their profession and confidence in discussing HPV; those with more years of experience in their profession being more confident about discussing HPV.

The findings from chapters 6 and 7 provide some first insight into the attitudes of medical health professionals about discussing HPV. The implications of the findings from chapters 6 and 7 demonstrate that there is a need for further education in health professionals, as well as the need for information that they can use as a plan and that they can give to their patients.

Discussing HPV with patients is important not only for ethical reasons (Shuman & Wolf, 2010), but also to ensure they have a trustworthy and reliable source of information, and health professionals have been viewed as such (Garner et al., 2012). The findings from chapter 7 also demonstrate areas to target for facilitating the discussions between health professionals and their patients about HPV. The three components of the COM-B model that were shown to be associated with willingness to discuss HPV in the future should be the areas focused on for behavioural interventions and training with health professionals.

10.2.6 What is the psychosocial impact on patients being diagnosed with HPV-OSCC?

Chapter 8 (study 5) presents findings from a qualitative interview study with patients diagnosed with HPV-OSCC. Only 12 of the 20 patients interviewed knew that their OSCC was caused by HPV, demonstrating that patients are not being routinely told the cause of their cancer despite health professionals knowing this as it is on their medical records, which has also been found previously (D'Souza et al., 2016; Milbury et al., 2013). All patients were diagnosed with oropharyngeal cancers with primary tumours in their tonsil or the base of tongue. Ten patients received multimodality treatment, eight received radiation alone and one received surgery alone.

Cancer is still perceived as a 'scary word' and feelings described by the patients in chapter 8 (study 5) were a mixture of being positive and being frightened by the diagnosis. Findings presented in chapter 2 demonstrated the challenges associated with HNC and that HNC

patients may isolate themselves (Dhooper, 1985) and may struggle with a loss of meaning in the context of their illness (Moore et al., 2004). Those patients who knew they were HPV-positive did not always find out from their health professional, which led to feelings of confusion and embarrassment. Reactions to their HPV diagnosis were mixed and some patients recognised stigma against HPV, supporting findings from the cervical cancer screening literature (McCaffery et al., 2006), whereas other patients were not bothered about the cause of their cancer and they were more concerned about their prognosis. Previous work with a small number of men in the HPV-OSCC population found concerns to be more cancer-related than HPV-related (Baxi et al., 2012) and the findings from chapter 8 (study 5) would also suggest this. Patients who also had young children, especially boys, were concerned about them being at greater risk of HPV and that they would not be offered the HPV vaccine as part of the current national immunisation programme. There is the potential that if the vaccine is proven to be effective against oral HPV as well as genital HPV, as some preliminary results may suggest (Grun et al., 2015; Herrero et al., 2013), vaccinating boys could eradicate HPV-OSCC in the future. Some patients were reluctant to discuss HPV with others, some due to the negative reactions of other people and some due to only being comfortable discussing HPV with medical professionals. This supports previous findings from the cervical cancer screening literature, where women have chosen not to disclose their HPV-positive test result as they were concerned about the reactions of others regarding stigma and shame, and that it could be a sign they had been unfaithful (Kahn et al., 2005).

The information given to patients about HPV varied, but there was a good level of understanding of HPV among the patients and they expressed that they would like to be told the information at the beginning, once they have been given their diagnosis. Patients were reassured by the information that the prognosis was better and that HPV is so common, supporting previous research (Baxi et al., 2012; D'Souza et al., 2016). Some patients also worried about the transmission of HPV to their partner, which has also been found in the cervical cancer literature (Clarke et al., 1996; McCaffery et al., 2006; McCaffery & Irwig, 2005).

Patients described how their diagnosis had given them “a different perspective”, being more focused and aware of their health, realising that life is too short and some described themselves as being ‘a better person’. These feelings around ‘seeing the world differently’ have been described in previous research with HNC cancer patients (Parker et al., 2013). The

psychological impact described by the patients in chapter 8 (study 5), were similar to those found in previous qualitative research with HNC patients (Baxi et al., 2012; De Boer et al., 1999; Lang et al., 2013).

Patients also described loss of confidence, feeling alone and isolated, embarrassment about how things had changed, relief about clear test results, stress and the feeling that nothing is normal. Some patients also described themselves as feeling lucky. Patients explained how socially they had to cancel plans they had made, felt that people acted differently following their diagnosis and how the difficulties with eating and drinking affected their social plans. Hobbies were also affected. These findings reiterate some of the previous research with HNC patients, particularly the dysfunction associated with HNC and the associated difficulties experienced as a result (Chaukar et al., 2009; De Boer et al., 1999).

The Transactional Model of Stress and Coping could be used to predict adjustment in HPV-OSCC patients and could be utilised in future research. The model suggests that patients' primary appraisal of HPV-OSCC would involve their perceptions of susceptibility and severity of their diagnosis, how much this may impact their lives, and how much they are to blame for their diagnosis. Patients also perceive how much control they have over their prognosis and their emotions as well as their ability to deal with their diagnosis. These two appraisal systems in turn influence how patients cope and how they adapt. Therefore interventions with patients at an early stage and ensuring they have all the information to meet their concerns may in turn influence their appraisal of the stressor and consequently their coping strategies, and how they adjust to their diagnosis.

The findings from chapter 8 (study 5) suggest that there are few concerns about HPV in those diagnosed with HPV-OSCC, but that they do seek further information about what HPV is. As many of the concerns associated with the psychosocial impact of HPV-OSCC were those related to dysfunction associated with its treatment, it is important to consider that if the de-escalation trials (see section 1.6) demonstrate that HPV-OSCC patients can receive less intensive treatment, then the treatment effects may not be as great and this could alleviate some of the psychological impact of HNC. These findings therefore have implications for practice, as to be able to offer HPV-OSCC patients a less intensive treatment would require health professionals to discuss HPV with patients at the time of their diagnosis.

10.2.7 What is the psychosocial impact on partners of patients who have been diagnosed with HPV-OSCC?

Chapter 8 (study 5) also presents findings from interviews with 12 partners of patients who had been diagnosed with HPV-OSCC. There were differing reactions to the cause of their partners' cancer, with one partner dismissing HPV as the cause, whereas other partners were open to talking about it with their friends especially when their friends assumed it was related to smoking. The disclosure from Michael Douglas was mentioned in some of the interviews as having a negative impact on how open partners were to their friends once Michael Douglas had disclosed his throat cancer was caused by oral sex. This demonstrates the altering perceptions of HPV through the information presented in the media, such as that shown in study 2. The risk of transmission was brought up in some interviews.

Partners became carers, but saw this as their role and that they did not want anyone else to do it. Concerns and feelings expressed by partners were most often about their ability to be strong for their partner and their family. A couple of participants had expressed wanting to talk to someone but did not use any support, supporting previous research that found 40% of caregivers who would have liked to have received psychological support (Richardson et al., 2015a). Active coping strategies, such as taking control, were apparent in some partners as a way of coping and to find out as much as they could. This has been found previously, as caregivers want to improve their understanding about HNC and its treatment (Richardson et al., 2015a). This would involve 'dragging' patients out of the house to go for their treatment when they did not want to go and searching for further information about HPV to help to reassure their partner and to find out as much as possible. Some patients felt like they were in the way during consultations and sometimes felt guilty if it was them asking all the questions. It was also evident that partners were essential in the dissemination of information to other family members and the need to keep them up-to-date. Another impact evident from the interviews with partners was their role in preparing food for the patient, how this was stressful and not easy.

The impact of being a carer for their partner did not always have negative implications, with one partner demonstrating it having a positive effect as he was now more independent. Positive experiences of caregiving have been found across a range of caregiving types (e.g. Cohen, Colantonio, & Vernich, 2002; Mackenzie & Greenwood, 2012).

The findings from interviewing partners of patients diagnosed with HPV-OSCC details a unique perspective which has not yet been studied in the field of HPV and HNC. As with previous research with caregivers, the impact upon these partners is substantial, as they take on the role of carer as well as managing everything else in their day-to-day lives (Röing et al., 2008; Watt-Watson & Graydon, 1995). The implications of the findings of this study are that support should not only be available for patients, but also for their partners. Partners and caregivers should also be involved in the dissemination of information about HPV and other aspects of HNC, as they often seek out this information to provide a supportive role for their partner.

10.2.8 The development of an information booklet

The results from all the research studies were considered in the development of the information booklet in chapter 9 (study 6). This information booklet aimed to accumulate evidence from the existing literature to answer frequently asked questions from patients and to develop an information resource that could be used by health professionals with their patients in consultations to aid the discussion of HPV. The information booklet was well received by patients, with every patient who reviewed the booklet saying that they would have liked to have received the booklet when they were diagnosed. Aspects of the booklet that patients particularly liked were that although the language was easy to read it remained professional, the layout of the booklet such that the order of the questions in the booklet are in the order they are likely to be asked, and the use of headings allows you to find sections easily and quickly. One patient particularly liked the guide on how to pronounce oropharyngeal. Patients were also very helpful in their feedback about additional information they would like to see in the booklet and also when there was a need for something to be explained further. It is important to involve patients in the development of information booklets such as this so that their understanding of what is being communicated can be examined and the content of the materials can be revised based on their feedback (Rudd et al., 2004).

The implications for the development of the information booklet are for further evaluation. As the information booklet has only been assessed against its readability and not for comprehension of the booklet, patients need to be involved in cognitive studies to assess how comprehensive the materials are. Previous studies have involved users in testing the comprehension of information materials (Hersch et al., 2014; Raynor, Knapp, Silcock, Parkinson, & Feeney, 2011) which have

involved interviews with users to assess comprehension of key content. For the information booklet to be used successfully within NHS consultations, it will be necessary for the information to also be assessed within this setting to measure its feasibility in this context. It will also be necessary to gain information on the views of health professionals using the information and whether this has increased their capability, opportunity and motivation for discussing HPV, and in turn increased their willingness to do so. The implications the provision of this information booklet could have include increasing knowledge of the relationship between HPV and HNC among the patient and health professional population and the potential to increase confidence of discussing HPV in health professionals. It is hoped that if implemented into HNC clinics in the NHS that patients will receive further information about their diagnosis as soon as they are diagnosed and this will help to prevent any negative psychological impact associated with HPV. It is also hoped that this booklet will become an important information resource for health professionals that could also facilitate training.

10.3 Summary of implications

The studies conducted in this thesis have shown that prior to this thesis, little was known about the psychological impact of HPV in HNC. These studies have demonstrated that the psychological impact of a diagnosis of HPV-OSCC is significant, but that it is usually overshadowed by concerns about OSCC and its treatment. This has implications for the importance of establishing appropriate support or resources for patients, as well as for their partners or caregivers. Knowledge of HPV as a cause or a risk factor for HNC in the general population is relatively low, but the level of awareness in the UK is still unknown and the basic facts about HPV and HNC were missing from coverage in the media. These findings could guide public health campaigns to generate a greater level of understanding and education among the public, which also has implications as there is currently no method through oral HPV testing of identifying populations who are at high risk of HPV-OSCC. This also has implications for possibilities of an oral cancer screening programme. Currently, HPV-OSCC fails to meet the criteria necessary for an effective and appropriate screening programme (Wilson & Jungner, 1968). The incidence and natural history is not understood, there is no validated screening test, there is no effective intervention if oral HPV is detected, and there is no evidence from RCTs that a screening programme would be effective in reducing mortality or morbidity. Technological

advances could lead to developments towards meeting these criteria and population-level oral cancer screening may be possible in the future, or if it is possible to identify criteria which enables us to stratify individuals at high-risk, these high-risk groups could be the focus of the screening programmes.

Health professionals are experiencing a different type of HNC patient now and this is having clinical implications for them in terms of patients' need for expedited rehabilitation. The implications of the potential availability of de-escalated treatment bear promise for lessened after-effects from the treatment. Some health professionals lack the knowledge and confidence to discuss HPV with their patients and it is hoped that the provision of the information booklet developed in chapter 9 (study 6) will aid in their discussions about HPV with patients. Although the incidence of HPV-OSCC is increasing, it is still not a common cancer but may overtake cervical cancer by 2020 (Chaturvedi et al., 2011) and it may be that health professionals do not see that many patients. If the incidence trends continue to increase and surpass cervical cancer, a secondary prevention strategy will be needed. It is however vital that GPs are aware of the changing demographic of HNC patients so that patients are not dismissed if they attend to their GP with symptoms of HNC.

10.4 Limitations

I have discussed the limitations of my studies in each chapter, but I will highlight here some limitations that apply across my whole thesis.

10.4.1 Participants

Chapters 6, 7, 8 and 9 involved the recruitment of participants. Participants recruited to research studies are likely to be research driven and those most willing to participate. This has implications for response bias, as there is the potential that participants who took part may have different experiences and knowledge to those participants who were not recruited. For example, health professionals recruited in chapter 6 may be more positive about discussing HPV with patients compared to those health professionals who did not want to take part and therefore a full breadth of understanding may not be possible. Social-desirability is possible, but unlikely for the participants recruited in chapters 6 and 8 as these involved in-depth interviews where it is more difficult to answer questions in a socially desirable manner as opposed to with true

experiences. Additionally, the participants recruited for chapter 7 were recruited anonymously and so this should have enabled the participants to feel comfortable answering truthfully and not as they thought I would like them to answer. The experts and patients recruited to provide feedback for the information booklet in chapter 9 may have been influenced by knowing that I developed the information, but as there were critical comments given by both experts and patients, this is unlikely.

Participants recruited in chapter 6 were health professionals working with HPV-OSCC patients across the UK, but the subgroups of health professionals were not large enough to make comparisons across the health professions. Participants recruited in chapter 7 were recruited through opportunistic sampling and it was not possible to calculate a response rate, so the findings might not be generalisable to the population. The sample size achieved did reach the number needed to detect a medium effect size in the analyses. Participants recruited in chapters 6 and 7 may have been those already more interested in or knowledgeable about HPV. Participants in chapter 8 were recruited at least one year after they or their partner had been diagnosed with their cancer and therefore some of their recollections may not be as vivid or accurate as if they would have been interviewed closer to the time of their diagnosis.

10.4.2 Methodology

Methods used for analysis in some of the chapters in this thesis can be viewed as subjective. The methodology used to assess the quality of the studies eligible for inclusion in the systematic review in chapter 4 was subjective, although by a member of my supervisory panel also coding ten per cent of the eligible studies, this strengthens the ratings given to each study as we were in agreement. Chapters 5, 6 and 8 involved qualitative analysis. As this was a new field of research, the aim was to present a snapshot and a greater depth of experiences, thoughts and feelings. Although qualitative research is not aimed at producing findings that are representative of the whole population, this was the most appropriate methodology for four of the research questions addressed in this thesis. Reliability and validity in qualitative research are often termed as quality, trustworthiness and rigour (Golafshani, 2003). As the interpretation of the data is subjective, qualitative research requires methods of demonstrating trustworthiness of the findings (Noble & Smith, 2015). Measures were taken in chapters 5, 6 and 8 to demonstrate reliability of the findings by recognising any sources of bias in the sampling, including verbatim

descriptions from participants in the results to support the interpretive findings, and by engaging with members of my supervisory panel during the analysis to reduce researcher bias.

There are also confounding factors which need to be considered in the studies conducted in this thesis. In chapter 4, the studies included were from a number of different countries, across a range of populations and so it is difficult to draw firm conclusions. The sample sizes in some of the studies included were also small and so may not be representative of the population in that country. There were also limits to the forward citation searches conducted as I was limited by which papers were currently included on Scopus which may have led to some of the most recent papers not being found and consequently not included. In chapter 5, the analysis of the content of UK media publications provides an overview of the information provided to the public, but no conclusions can be drawn from these findings to knowledge of the general population. The general population has access to many other media outlets, as well as the media in other countries, and in addition to social media. All these other outlets of information could affect knowledge in the UK of the relationship between HPV and HNC.

10.4.3 Materials and measures

The items used to assess health professionals knowledge, experience and attitudes in chapter 7 were not from a validated scale. Seven of the items on the knowledge scale were selected from a validated scale, but then combined with items from an unvalidated scale. Measured using Cronbach's Alpha, the reliability of the 12 item scale in this sample was questionable ($\alpha=0.62$) (George & Mallery, 2003). Even when splitting these into two scales and measuring the reliability separately, the reliability did not improve. There is a need for a validated scale to measure knowledge of HPV and HNC in the UK, as there is currently no data available about levels of knowledge in the UK.

In chapter 9 there was no formal evaluation of the information booklet due to time constraints. The readability scores should be interpreted with caution as they do not indicate any level of comprehension from the patients, but there was reassuring feedback from the patients indicating that they found the information presented easy to understand.

10.4.4 Research and researcher effects

It is important to recognise the influence that research and myself as a researcher could have had on the research findings. As all the participants involved in any of the studies included in this thesis were aware that they were taking part in research towards my PhD, this may have influenced how they responded.

As previously mentioned, qualitative analysis is subjective and so the results of chapters 5, 6 and 8 are likely to have been influenced by my pre-existing perceptions of what may have been presented in the media, what experiences health professionals had had with patients and what patients and their partners may express as the impact of their diagnosis. These researcher effects should have been reduced by introducing members of my supervisory panel to also code some of the analysis and also by providing verbatim quotes as examples in the results sections of these three chapters, this will have enabled the reader to also interpret them.

10.5 Future research

10.5.1 Further psychosocial research with patients

As discussed in the previous chapters of my thesis, this is only the beginning of research into the psychosocial impact of HPV in the HNC context in the UK. A great deal of further research needs to be done with a larger volume of patients, which would be possible if standardised psychological measures were part of standard clinical practice. It would also be useful, if ethically possible, to interview patients or ask them a few short questions shortly after they are told they have HPV-OSCC to gain insights on their immediate responses and not those at least one year post diagnosis. Alternatively, recruiting HPV-OSCC patients to complete a quantitative measure assessing their reactions to testing positive for HPV and the psychosocial impact of this, would enable an evaluation of the psychosocial impact of testing positive for HPV in a larger number of patients and so would provide a wider spread of data on which to base recommendations.

10.5.2 Further evaluation of the information booklet

As mentioned previously in chapter 9, the information booklet needs to be evaluated with patients and health professionals to assess its comprehension in patients and its feasibility of

use with health professionals. It would also be beneficial to investigate the impact of the booklet on patients' understanding of HPV as well as on the emotional impact of testing positive for HPV. The booklet could be implemented into use into NHS head and neck cancer clinics as a discussion tool for health professionals.

The information booklet could also be adapted for use in other populations such as the general public, to improve knowledge about HPV-OSCC.

10.5.3 Knowledge of HPV and HNC

As illustrated in this thesis, there has been no research published in the UK to assess knowledge of HPV as a cause of HNC. The development of a validated scale to measure knowledge of HPV-OSCC would be optimal so that knowledge could be compared across different populations and gaps in knowledge could be identified. By having a validated measure this could also assess knowledge in populations at different time points, in health professionals in particular and could be used to assess the effectiveness of interventions or training aimed at increasing knowledge. The Cancer Awareness Measure (CAM) is a validated, standardised measurement tool for assessing cancer awareness (Stubblings et al., 2009) and has since been developed for measurement of awareness of specific cancers (Linsell et al., 2010; Power, Simon, Juszczuk, Hiom, & Wardle, 2011; Simon, Juszczuk, et al., 2012; Simon, Wardle, et al., 2012), but one has yet to be developed for HNC.

It would also be interesting to assess knowledge in the patient population and whether knowledge is associated with improved psychosocial outcomes.

10.5.4 Measure oral sex practices

As one of the theories behind the increase in HPV-related HNC is the increase in oral sexual practices, it would be interesting to monitor whether the levels of oral sex are reported to have decreased with the increasing awareness that HPV is a cause of HNC and that oral sex is likely to be the reason why. The National Surveys of Sexual Attitudes and Lifestyles study in the UK asks about oral sex behaviour, but only takes place every ten years and so would not be due to be delivered again until 2020-2022. There is a possibility that in this time the relationship between HPV and HNC will be more widely known. Awareness of HPV as a risk factor for

cervical cancer in the UK increased in women from the general population from 0.9% (recall) in 2002 (Waller et al., 2004), to 61.6% (recognition) in 2011 (Marlow et al., 2013) and there is the possibility that awareness of HPV as a risk factor for HNC could increase by similar margins over the next ten years. However, the rise in awareness of HPV as a risk factor in cervical cancer is likely due to the cervical cancer national screening programme and the marketing of the HPV vaccine as the 'cervical cancer' vaccine. Unless a screening programme is introduced to screen for oral HPV or the HPV vaccine is extended to be given to boys, awareness of the relationship between HPV and HNC to the same level of HPV and cervical cancer may not be likely.

10.5.5 Interventions for health professionals

As health professionals have demonstrated a lack of confidence in discussing HPV with their HNC patients, it would be warranted to develop some behaviour change interventions, possibly using the COM-B model. These interventions could focus on increasing knowledge, confidence and demonstrating the reasons it is important to discuss HPV with patients in an effort to facilitate the discussion of HPV. As discussed in chapter 7, the Theoretical Domains Frameworks could be a useful approach for identifying HPV-related clinical behaviours that need targeting to develop an intervention to support health professionals when discussing HPV with their patients.

10.5.6 Future research using theory

Theory can be useful to help guide and focus research and accumulate knowledge about health outcomes. As discussed in this thesis, models such as the CSM and the Transactional Model of Stress and Coping could be useful models in the design of future research studies to help explain the different ways patients appraise their diagnosis of HPV-OSCC and the ways in which coping strategies can influence patients' adjustment to their diagnosis.

Models of behaviour change such as the COM-B model or the IMB model could also be used in the design of future studies to identify key components to target in the development of interventions for health professionals to facilitate the discussions of HPV with their patients. There are a number of resources available using the components of the COM-B model which are designed to provide insight into what health professionals would need to do in order to

change their behaviour (Michie et al., 2005) in the development of interventions. This would be a useful starting point for future interventions developed for health professionals caring for patients with HPV-OSCC.

10.6 Final conclusions

Prior to starting my thesis, research examining the psychological impact of HPV-OSCC in the UK did not exist. My thesis neatly examines the literature currently available and firsthand the experiences of health professionals, patients and their partners affected by this particular type of HNC which is on the increase. It is evident that health professionals need further training for discussing HPV with HNC patients and that patients and their partners should be told the cause of their cancer if an HPV test of their tumour is conducted. The information needs of patients and their partners could begin to be met with the introduction of the information booklet developed as part of this thesis and this may go some way to providing a discussion tool for health professionals. As many of the patients' concerns in this thesis were about their cancer and its treatment, it is also important that with the introduction of the HPV element, that this is not forgotten. It is uncertain whether this subgroup of HNC patients will begin to be offered less intensive treatment in the future, but if this is to be the case, some of the psychosocial effects on this patient group may be alleviated if the after-effects of the treatment are not so severe. Communicating to patients the key messages about HPV-OSCC found in this thesis could have implications for the psychological health of HPV-OSCC patients in the future.

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APPENDICES

APPENDIX 1.1: ONGOING DEINTENSIFICATION TRIALS IN HPV-OPSCC

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Trial	Primary Outcome	HPV testing	Inclusion Criteria	Treatment	Primary Completion Date
ECOG 1308 United States	2-yr OS	HPV PCR	Stage III/IVA-IVB oropharyngeal SCC	Low-dose IMRT (50 Gy x 27 fractions) + cetuximab vs standard-dose IMRT (60 Gy x 33 fractions)	2015
NRG 002 United States	2-yr PFS	p16 IHC	Stage III/IV A, B, or C (T1-T2, N1-N2b or T3, N0-N2b); <10 pack-years smoking	IMRT (60 Gy x 30 fractions) ± cisplatin	2018
RTOG 1016 United States	5-yr OS	p16 IHC	Stage III/IV oropharyngeal SCC	IMRT (60 Gy, day1-4 once daily, day 5 twice daily) and high-dose cisplatin day 1 and 22 vs weekly cetuximab x 7 weeks	2020 (primary accrual completed)
UMCC Michigan, United States	Recurrence rate	HPV testing or p16 IHC	Stage III/IV (excluding N3 or T4); <10 pack-years smoking	Standard-dose RT (70 Gy x 35 fractions) + cetuximab	2020
TROG 12.01 Australia	Symptom severity	p16 IHC	Stage III (excluding T1-2N1) or stage IV (excluding T4, N3 and distant metastasis); ≤ 10 pack-years smoking (if > 10 pack-years, must be N0-N2a)	Standard-dose RT (70 Gy x 35 fractions) + weekly cetuximab or cisplatin	2020
De-ESCALATE United Kingdom	Severe toxicity	p16 IHC	Stage III/IVA (T3N0-T4N0 and T1N1-T4N3), except N2b, N2c or N3; > 10 pack-years smoking	Standard-dose RT + weekly cetuximab or 3 doses of cisplatin	2017

Trial	Primary Outcome	HPV testing	Inclusion Criteria	Treatment	Primary Completion Date
ECOG 3311 United States	2-yr PFS	p16 IHC	Stage III/IV A or B (low risk, intermediate risk, and high risk)	<ul style="list-style-type: none"> • Low risk: surgery + observation • Intermediate risk: surgery + low-dose RT (50 Gy x 25 fractions) vs standard-dose RT (60 Gy x 30 fractions) • High risk: surgery + standard-dose RT (60-70 Gy x 30-35 fractions) + weekly cisplatin or carboplatin 	2016
SIRS New York, United States	3-yr and 5-yr DFS, locoregional control	HPV PCR	<ul style="list-style-type: none"> • Low risk: complete resection; no LVI, PNI, or ECS; no matted or low nodes • Intermediate risk: complete resection; +LVI, +PNI; < 3 positive nodes; ≤ 1-mm ECS • High risk: incomplete resection; 3+ nodes; ≥ 1-mm ECS; matted or supraclavicular nodes 	<ul style="list-style-type: none"> • Low risk: observation • Intermediate risk: RT • High risk: concurrent chemotherapy 	2019
ADEPT Multistate, United States	2-yr DFS, locoregional control	p16 IHC	T1-4a, N+, +ECS with negative margins after resection	Standard-dose RT (60 Gy x 30 fractions) ± weekly cisplatin	2018
ORATOR Ontario, Canada	1-yr QoL	p16 IHC	T1-2, N0-2 with negative margins after resection (TORS)	Standard-dose RT (70 Gy x 30 fractions) ± chemotherapy	2021

HPV-OPSCC=HPV-mediated oropharyngeal squamous cell carcinoma; DFS=disease-free survival; ECOG=Eastern Cooperative Oncology Group; ECS=extracapsular spread; IHC=immunohistochemistry; IMRT=intensity-modulated radiation therapy; LVI=lymphovascular invasion; ORATOR=oropharyngeal cancer radiation vs TORS; OS=overall survival; PCR=polymerase chain reaction; PFS=progression-free survival; PNI=perineural invasion; QOL=quality of life; RT=radiation therapy; RTOG=Radiation Therapy Oncology Group; SCC=squamous cell carcinoma; SIRS=Sinai robotic surgery; TORS=transoral robotic surgery; TROG=Trans Tasman Radiation Oncology Group; UMCC=University of Michigan Comprehensive Cancer Center

APPENDIX 4.1: STUDY 1 - PUBLISHED PAPER

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Overview

Human Papillomavirus and Head and Neck Cancer: Psychosocial Impact in Patients and Knowledge of the Link – A Systematic Review



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Abstract

Head and neck cancer (HNC) currently affects approximately 11 200 people in the UK, with an increasing proportion known to be caused by the human papillomavirus (HPV). We undertook a systematic review of studies measuring the psychosocial impact of HPV-related HNC and also studies measuring knowledge about the link between HPV and HNC among different populations. Searches were conducted on MEDLINE, Embase, PsycINFO, CINAHL Plus and Web of Science, with reference and forward citation searches also carried out on included studies. Studies were selected if they (i) were original peer-reviewed research (qualitative or quantitative), (ii) mentioned HPV and HNC, (iii) measured an aspect of the psychosocial impact of the diagnosis of HPV-related HNC as the dependent variable and/or (iv) measured knowledge of the association between HPV and HNC. In total, 51 papers met the inclusion criteria; 10 measuring psychosocial aspects and 41 measuring knowledge of the link between HPV and HNC. Quality of life in those with HPV-positive HNC was found to be higher, lower or equivalent to those with HPV-negative HNC. Longitudinal studies found quality of life in patients was at its lowest 2–3 months after diagnosis and some studies found quality of life almost returned to baseline levels after 12 months. Knowledge of the link between HPV and HNC was measured among different populations, with the lowest knowledge in the general population and highest in medical and dental professionals. Due to the limited studies carried out with patients measuring the psychosocial impact of a diagnosis of HPV-positive HNC, future work is needed with the partners of HPV-positive HNC patients and health professionals caring for these patients. The limited knowledge of the association between HPV and HNC among the general population also indicates the need for research to explore the information that these populations are receiving.

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Key words: Head and neck cancer; HPV; human papillomavirus; knowledge; quality of life

Statement of Search Strategies Used and Sources of Information

We searched MEDLINE, Embase, PsycINFO, CINAHL Plus and Web of Science using relevant search terms for the overview. There were no language or date restrictions applied to the search. All references were reviewed against the inclusion and exclusion criteria. Additional relevant papers were found through searching the reference lists of included studies and carrying out forward citation searches on included studies.

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Introduction

Head and neck cancer (HNC) affects about 11 200 people in the UK each year [1–4] and there are currently 62 500 survivors of the disease [5]. Diagnosis is associated with well-recognised psychosocial sequelae, including difficulties with communication with the partner, functioning in the family, and social and interpersonal relationships [6]. Patients have also been found to isolate themselves from their friends and family due to the disfiguring impact of treatment on their appearance [7], and many feel stigmatised [8]. Practical issues, such as problems with speaking, can also interfere with communication, and poorer communication has been found to result in greater distress [9]. Negative psychological consequences tend to be worse for patients undergoing surgery than those receiving alternative methods of treatment [10–12].

It is now clear that an increasing proportion of HNC cases are caused by the human papillomavirus (HPV) [13–16], which has long been associated with cervical and other anogenital cancers [17]. The incidence of HPV-related HNC is rising [18], with numbers in the USA set to surpass the numbers of cervical cancer cases by 2020 if the current trend continues [19]. Patients with HPV-positive HNC are typically younger than those with HPV-negative disease, and tend to be white, male, married, educated and employed [20]. Risk factors are thought to be a greater lifetime number of sexual and oral sex partners [20–23] due to greater exposure to HPV.

We know from the cervical cancer literature that the sexually transmitted nature of HPV can lead to additional psychological challenges to those associated with the cancer itself. Women have felt stigma, anxiety, concern about their relationships and worry about disclosure of their test results to others, following a diagnosis of HPV in the context of cervical screening [24]. As the link between HPV and HNC has been established, there has been increasing recognition of the need for guidance on how to discuss HPV with patients [25–27]. Behavioural and psychological science has made a significant contribution to understanding and addressing psychosocial issues associated with both HNC and HPV. One study measuring the supportive care needs of HNC patients found overwhelming evidence of unmet psychological needs [28] and a Cochrane review paper found a number of randomised controlled trials implementing psychosocial interventions for HNC patients, but concluded there was not enough evidence to conclude on their effectiveness [29]. It is also important to assess knowledge of the association between HPV and HNC among different populations, to identify gaps in knowledge and inform communication strategies.

Research has started to explore what the public know about HPV and HNC and how an HPV diagnosis affects patients. Knowledge of HPV appears to have increased following the introduction of the HPV vaccination, which is now offered to adolescents in most developed countries [30]. In the context of cervical cancer, an online survey of adults in the UK, USA and Australia following the introduction of the HPV vaccination showed 61% reported having heard of HPV [31]. By contrast, public awareness of the signs and risk factors for HNC has been shown to be poor [32]. In the clinical context, few resources currently exist to answer patients' concerns about how, when and why they got their cancer [27], the answers to which can have implications both for the patient and their past, present or future partners.

This review is timely in drawing together findings from the emerging literature and identifying priorities for a behavioural science research agenda in this field. The evidence from both the cervical cancer and HNC literature suggests that there may be greater psychological distress in these patients due to the combination of both a diagnosis of cancer and of HPV. The review aims to answer two questions:

- (i) What is the psychological impact of an HPV diagnosis in the context of HNC?

- (ii) What is known about HPV-related HNC in different population groups?

Materials and Methods

Search Methods for Identification of Studies

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed for this systematic review [33]. Search terms were developed in consultation with a librarian at UCL and through extracting key terms from previous review papers and relevant primary research. Terms covered (i) the health condition of interest (e.g. HPV, human papillomavirus, head and neck cancer), (ii) psychosocial outcomes of interest (e.g. psychosocial, depression, anxiety, quality of life) and (iii) knowledge (e.g. knowledge, awareness). The full search strategies for each database can be found in the *Supplementary Material*. Initial search terms were later refined based on common text words from relevant articles retrieved from the search. MEDLINE, Embase and PsycINFO databases were accessed through Ovid databases and were searched from inception to present in December 2014. Search terms were adapted for CINAHL Plus and Web of Science. These databases were chosen based on previous review papers in this field and because all databases will complement each other and allow a broader scope of coverage. There were no language or date restrictions applied to the search. The reference lists of included studies were searched (RD) for additional relevant papers. The grey literature was also searched using OPENSIGLE (opensigle.inist.fr). Results of the literature search were downloaded into Endnote with duplicate articles removed.

Inclusion and Exclusion Criteria

Studies were included if they (i) were original peer-reviewed research (qualitative or quantitative), (ii) mentioned HPV and HNC, (iii) measured an aspect of the psychosocial impact of the diagnosis of HPV-related HNC as the dependent variable and/or (iv) measured knowledge of the association between HPV and HNC. Studies were excluded if they were not written in English, did not report original research or were conference abstracts.

Selection Procedure and Quality Assessment

Article titles were screened by two authors (RD, JW) and were excluded if they were not written in the English language or were clearly irrelevant to the review. Two members of the review team (RD, LM) then screened the abstracts of the remaining articles, looking more specifically for articles mentioning HPV. Authors of conference abstracts that appeared to meet the eligibility criteria were contacted to request a copy of the full paper if it was available. Those not submitted or published in peer-review

journals were excluded and one author did not reply after multiple attempts to contact them, so this paper was also excluded. Disagreements were resolved by discussion and reasons for inclusion/exclusion were noted. Articles that appeared to meet the inclusion criteria based on the title

and abstract screen were obtained for full-text review (Figure 1). Copies of articles that could not be assessed for relevance based on the title and abstract screen were also obtained to determine eligibility based on full-text review.

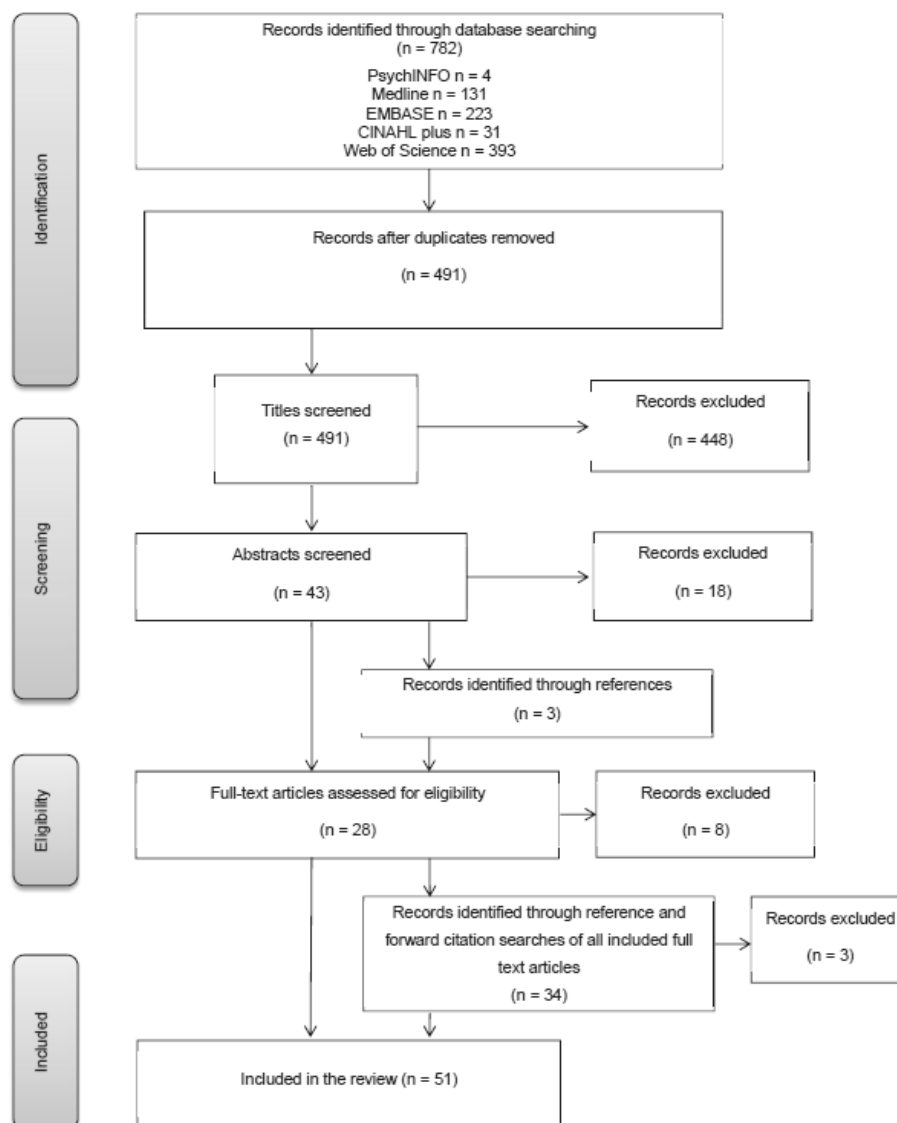


Fig 1. Flow diagram of study selection (adapted from [33]).

A full-text eligibility review was conducted by two members of the review team (RD, LM) with reasons for exclusion recorded. Reasons for excluding studies included the article not containing any original data relevant to our eligibility criteria, not mentioning HPV or not measuring our outcomes of interest as dependent variables. Forward citation searches were conducted for all papers obtained for full-text review and included those published up to August 2015. Eligibility of articles found through forward citation and reference searching was confirmed by a second screener (LM). A summary of the data from all full-text articles was extracted (Tables 1, 2) into Microsoft Excel and the quality of the studies was assessed using an amended version of the National Institute for Health and Care Excellence (NICE) quality appraisal checklists for quantitative and qualitative studies [34]. This considered a range of factors, which included whether the source population was well described, whether the outcome measures were reliable and relevant, whether the analytical methods were appropriate and whether the findings could be generalised to the source population.

Analysis

Data from all included articles were recorded using a data extraction form. The results from articles measuring psychosocial outcomes and knowledge are reported descriptively with comparisons drawn where appropriate. Qualitative findings are described separately.

Results

Search Results

The initial search returned 782 articles, which was reduced to 491 after the removal of duplicates; 448 were excluded on the basis of their title, leaving 43 abstracts to be reviewed. Once the articles had been screened by title and abstract, 25 were obtained for full-text review. An additional 37 articles were included after searching the reference lists, relevant review papers found through the search and searching forward citations of those already obtained for full-text review. Eleven articles were excluded during full-text review, leaving 51 papers included in the final analysis. Figure 1 shows the study selection process. All the authors agreed on the final papers included in the review.

Studies Assessing the Psychosocial Impact of Human Papillomavirus-related Head and Neck Cancer

Ten of the studies measured psychosocial outcomes [35–44]. Of these, eight were conducted in the USA [35,37–40,42–44], one was conducted in Switzerland [36] and one in Italy [41]. Quantitative studies used survey-based methods [36–38,40–44] and conducted an audit on medical records [39]. One article collected qualitative data from individual interviews [35]. All articles were published between 2012 and 2014. In some studies, p16 expression

was used as a marker of HPV status, but for simplicity we refer to patients as HPV-positive throughout the review.

The psychosocial impact of HPV-related HNC was measured in patients [35–44] at different time points in their care continuum from newly diagnosed [36,38,40,42,43], to up to 5 years post treatment completion [35].

Quality of Life Measures

Quality of life was the main outcome measure used in seven studies and was measured using a number of different tools. Six of the studies measuring quality of life used at least one HNC-specific measure (Table 3). Two studies used the Head and Neck Cancer Inventory (HNCI) [37,38], which is a validated 30-item survey measuring patient-reported quality of life status in speech, eating, aesthetics and social disruption. Three studies used the University of Washington Quality of Life (UWQOL) measure [40,43,44], which is a validated HNC-specific quality of life questionnaire including 12 domains, with two subscales of physical and social-emotional functioning. One study used the European Organization for Research and Treatment of Cancer (EORTC) HNC-specific version (QLQ-H&N35) [36], which includes seven scales measuring pain, swallowing, senses, speech, social eating, social contact and sexuality. One study used Head and Neck Quality of Life (HNQOL) [44], which measures the four domains of eating, communication, pain and emotion. Generic measures were also used in three studies and included the Medical Outcome Study Short Form 36 (SF-36) [44], which is a 36-item generic measure of health status split into 10 domains, the EQ-5D [41], which has five dimensions of measuring quality of life, and the EORTC general core questionnaire (QLQ-C30) [36] measuring activity, physical and social functioning. Other psychosocial measures used were the National Comprehensive Cancer Network's distress thermometer, which uses a scale from 0 to 10 for patients to indicate how much distress they have been experiencing in the last week, and the Glinder and Compas one-item measure of behavioural blame [42] (i.e. 'How much do you blame yourself for the kinds of things you did, that is, for any behaviours that may have led to your cancer?').

Studies with Human Papillomavirus-positive Patients Only

Three studies did not include a comparison between HPV-positive patients and HPV-negative patients [35,42,44]. The one qualitative study with HPV-positive HNC survivors reported that 3/10 cancer survivors felt a sense of stigma or shame associated with their diagnosis [35]. The second study measured distress and self-blame in newly diagnosed HPV-positive patients [42]. Distress levels were found to be moderate (mean 3.38, range 0–9), with 30% showing clinically meaningful scores (scores above or equal to 4). Self-blame levels were found to be low (mean 2.27, range 1–4). The third study measured quality of life using the UWQOL, HNQOL and SF-36 and found summary scores remained stable between 2 years and long-term follow-up (median of 78 months after the completion of treatment) [44]. Clinically meaningful (≥ 10 point change)

Table 1
Psychosocial studies included in the systematic review

Reference Country	Sample	HPV/ p16 positive	Study design	Outcomes/measures	Relevant findings
[35] USA	10 male survivors of HPV-OSCC between 1 and 5 years treatment completion	100% (HPV+)	Qualitative semi-structured interviews	Exploring the communication, comprehension and psychologic impact of a diagnosis of HPV-related oropharyngeal cancer	<ul style="list-style-type: none"> - 3/10 felt a sense of stigma or embarrassment associated with their diagnosis - The cancer itself occasionally or always overshadowed the impact of HPV - 4/10 were concerned with potentially infecting a partner with HPV and one expressed concerns about re-infection - Survivors understood and were encouraged by positive prognostic implications of an HPV diagnosis
[36] Switzerland	98 survivors of oropharyngeal cancer a median of 67 months after treatment	89% (p16+)	Follow-up survey (postal)	Quality of life: EORTC QLQ-C30 and EORTC QLQ-H&N35	p16+ patients had significantly lower scores on physical and role functions and had more complaints about feeling ill and pain than p16- patients
[37] USA	22 patients at first head and neck cancer clinic visit; 2 females, 20 males	80.9% (HPV+) 95.2% (p16+)	Longitudinal study: baseline (preoperatively), 3 weeks, 3 months, 6 months and 12 months	Quality of life: Head and Neck Cancer Inventory	<ul style="list-style-type: none"> - Speech, eating, aesthetics and social disruption scores at 3 weeks, 3 and 6 months were significantly lower than at baseline - Overall quality of life still significantly lower than preoperative levels at 1 year - Significant declines in overall quality of life at 3 months compared with 3 weeks - No significant impact on quality of life outcomes by HPV status - All health-related quality of life scores declined at 3 weeks; social and overall scores continued to drop and bottomed out at 3 months - Social and overall scores showed at 12 months greatest recovery significantly from baseline - No differences between HPV+ and HPV- patients on any of the quality of life domains at 12 months
[38] USA	87 patients at first new patient referral visit; 81 included in analysis	63% (HPV+) 74% (p16+)	Prospective cohort study	Quality of life: Head and Neck Cancer Inventory	<ul style="list-style-type: none"> - No significant differences between HPV+ and HPV- patients for rates of major depression or anxiety disorder - Higher prevalence of anxiety in HPV- patients
[39] USA	162 medical records – patients with locally advanced OSCC, known p16 status and treated by chemoradiation or primary surgery followed by adjuvant radiation therapy; 142 men, 20 women	69% (p16+)	Audit of medical records	Prevalence of anxiety disorder and major depression in patients with HPV+ and HPV- tumours	

(continued on next page)

Table 1 (continued)

Reference Country	Sample	HPV/p16 positive	Study design	Outcomes/measures	Relevant findings
[40] USA	177 patients with HNSCC and known HPV/p16 status diagnosed between 2006 and 2012	45% (p16+)	Longitudinal study: baseline, 2 months, 6 months, 1 year and 1–3 years	Quality of life: UWQOL	<ul style="list-style-type: none"> - p16+ patients had significantly better overall quality of life, recreation and chewing scores at baseline - p16+ patients had better activity, recreation, overall quality of life at 6 months - No long-term differences in quality of life for p16– patients treated with primary surgery or chemoradiation - Overall quality of life in patients significantly lower than healthy subjects - Utility scores were higher in men than women
[41] Italy	79 patients with HNSCC; 17 women, 62 men Control group: healthy subjects matched for gender and disease proportion attending same clinic for non-pathological reasons	100% (HPV+)	Multicentre, observational and retrospective study	Perception of their health conditions: EQ-5D Measurement of utility loss considering patient's perspective	
[42] USA	62 newly diagnosed HPV+ patients initiating radiotherapy	98% (p16+) 89% (HPV+)	Cross-sectional survey	Self-reported: <ul style="list-style-type: none"> - Feelings of keeping their HPV a secret from others - Disclosure of HPV to current sexual partner - Whether HPV increased partner's risk - Whether they talked to partner about likelihood of transmission - How much knowledge of HPV as a cause had impacted their relationship - Distress - Self-blame 	<ul style="list-style-type: none"> - About 30% showed marked distress - Distress levels were moderate - Patients reported low levels of behavioural self-blame - Blame and distress were significantly correlated - No significant differences regarding distress and self-blame in those self-declaring as HPV+ compared with those who did not or were unsure - 14% intended to keep it a secret from others and 3% did not tell their partner – reasons included embarrassment, stigma, and belief it is no-one else's business - 41% said they had not discussed concerns regarding potential viral transmission to their partner - 8% thought their HPV had entirely increased their partners risk for developing cancer, 42% said somewhat and 29% said it did not - 80% reported that the diagnosis had no negative impact, 14% reported a somewhat negative impact, 6% reported a completely negative impact on relationships
[43] USA	228 patients diagnosed with primary OSCC between 2003 and 2010 Group 1: (n = 162) HPV– and low-risk	29% (HPV+)	Longitudinal study: pre-treatment, immediate post-treatment and 1 year post-treatment	Quality of life: UWQOL	<ul style="list-style-type: none"> - Pre-treatment quality of life scores were significantly higher in patients who were high-risk HPV+ - Immediate post-treatment scores were lower in HPV+ patients - Post-treatment scores were similar between the two groups

<p>[44] USA</p>	<p>HPV Group 2: (n = 66) High-risk HPV+</p>	<p>40 head and neck cancer survivors >2 years after treatment; 34 men, 6 women</p>	<p>98% (HPV+)</p>	<p>Follow-up survey (postal)</p>	<p>Health-related quality of life: HNQOL, UWQOL, SF-36</p>	<ul style="list-style-type: none"> - Group 2 had a significantly larger decrease in quality of life scores from pre-treatment to immediate post-treatment compared with group 1 - The change in quality of life scores from post-treatment to 1 year post-treatment was similar between the groups - HPV status was associated with pre-treatment quality of life and a change in quality of life from pre-treatment to immediate post-treatment - Patients in group 2 did not have better 1 year quality of life compared with group 1 - Global HNQOL remained stable compared with 2 year assessments for HNQOL and UWQOL - Clinically meaningful declines in global HNQOL from 2 year assessment were reported by 8% of patients by HNQOL and 14% of patients by UWQOL - 8% on HNQOL and 11% on UWQOL reported meaningful improvements in global HNQOL - 84% and 75% of patients reported stable global HNQOL compared with 2 years by HNQOL and UWQOL - Overall physical and mental health mean scores on the SF-36 were comparable to US population norms in each HNQOL domain - Overall cohort experienced stable HNQOL scores and statistically worse UWQOL score compared to pre-treatment - Clinically meaningful declines were found in global HNQOL from pre-treatment by 8% on HNQOL and 30% on UWQOL
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HPV, human papillomavirus; HNSCC, head and neck squamous cell carcinoma; EORTC, European Organization for Research and Treatment of Cancer; UWQOL, University of Washington Quality of Life; HNQOL, Head and Neck Quality of Life; SF-36, Short Form 36; OSCC, Oropharyngeal squamous cell carcinoma.

declines in quality of life measured using the UWQOL was found in 14% of patients, whereas 11% of patients reported clinically meaningful improvements. Summary scores on this measure between pre-treatment and long-term follow-up were significantly worse. Clinically meaningful (≥ 10 point change) declines in quality of life measured using the HNQOL were found in 8% of patients, with 8% of patients reporting clinically meaningful improvements. Summary scores on this measure remained stable between pre-treatment and long-term follow-up. Scores on the SF-36 for long-term physical and mental health were comparable with the US population norms [44].

Cross-sectional Studies with a Comparison Group

One study compared quality of life in HPV-positive patients and HPV-negative patients using the EORTC QLQ-C30 [36]. Patients with HPV-positive tumours were found to score significantly better on physical and role functions of the scale [36], but there were no significant differences between the groups in the emotional, social and global health functions of the scale. In an audit of medical records, Hess and colleagues [39] found that there was a higher prevalence of anxiety in HPV-negative patients, but rates of major depression or anxiety disorder did not differ significantly between the HPV-positive and HPV-negative groups. Another study compared quality of life scores measured using the EQ-5D between HPV-positive patients and healthy subjects [41]. Overall quality of life was significantly lower in patients than in healthy subjects.

Longitudinal Studies with a Comparison Group

Four studies compared quality of life between HPV-positive and HPV-negative patients at more than one time point [37,38,40,43]. One study measuring quality of life using the UWQOL [40], found that overall quality of life scores were better at each time point for HPV-positive patients than for HPV-negative patients, with the differences being significant at baseline, 6 months and after 12 months. Another study measuring quality of life using the UWQOL [43] found that pre-treatment quality of life scores were significantly higher in HPV-positive patients compared with HPV-negative patients, lower (but not significantly) immediately after treatment and similar at 1 year after treatment. Quality of life measured using the HNCL in one study found that HPV-positive patients had a higher quality of life at baseline, but then a lower quality of life at 3 weeks, 3 months and 6 months compared with HPV-negative patients [37]. Another study using the HNCL found that HPV status was not associated with quality of life outcomes at 12 months [38]. Using data from the whole sample, clinically meaningful declines were found from baseline to 12 months in speech function, aesthetic attitude, eating function and attitude [38].

Overall, these longitudinal studies found inconsistent results when comparing quality of life in HPV-positive patients and HPV-negative patients. Some reported HPV-positive patients with a combination of both higher and

lower quality of life scores than HPV-negative patients depending on the time points ($n = 3$), with differences only significant when the quality of life scores were higher in HPV-positive patients. Others found no significant differences between the groups at any time point ($n = 2$).

Studies Assessing Knowledge of Human Papillomavirus-related Head and Neck Cancer

Forty-one papers from 37 studies assessed knowledge about HPV and HNC [45–85]. Over half ($n = 23$) were conducted in the USA [46–49,52,54,56,62,67–71,73–78,80,82–85], with others from Germany ($n = 4$) [58–61], Saudi Arabia ($n = 3$) [63–65], Canada ($n = 2$) [50,66], Malaysia ($n = 2$) [79,81], Jordan ($n = 2$) [45,57], Italy ($n = 1$) [72], Puerto Rico ($n = 1$) [51], Romania ($n = 1$) [55] and Ireland ($n = 1$) [53]. All were published between 2002 and 2015. Quantitative studies ($n = 40$) [45–51,53–85] used survey-based data collection methods and one qualitative study collected data using focus groups [52].

Studies assessing knowledge of HPV and HNC included samples of dental students [48,49,55,65,81], medical students [64,74,81,85], general undergraduate students [66,82,83,85], oral health providers (dentists and dental hygienists) [46,50,52,53,58–60,69,71,75,79], head and neck surgeons [68], healthcare professionals [57,61,63,75], a population-based sample of US men [47,76] and a population-based sample of US adults [54,67,73,78,80]. Some specific sample populations were included, such as American Indian community members [56], bisexual and homosexual populations [62,72,77,84] and National Association for Stock Car Auto Racing (NASCAR) fans [85].

Knowledge of the association between HPV and HNC varied across study populations and the questions asked (Table 4). All the questions involved recognition of HPV as either a cause or a risk factor for oral cancer, with no studies requiring participants to recall HPV as a risk factor for oral cancer. For example, Hertrampf and colleagues [58–61] asked 'Which of the following factors places an individual at high risk for oral cancers?' with HPV listed as a response option and Colón-López and colleagues [51] asked participants to respond true or false to the statement 'HPV is associated with oral cancer'. Knowledge of HPV as a risk factor for oral cancer ranged from 26 to 91% in medical or dental professional samples [45,46,50,53,57–61,63,68,69,71,75,79] compared with between 1 and 44% in samples of members of the general population [51,54,56,60,62,67,70,72,73,76,77,80,84,47,78]. Knowledge among students ranged from 18% in general undergraduate students to 84% in undergraduate dental students [48,49,55,64–66,74,81–83].

Quality Assessment

Based on the NICE quality appraisal checklists for the quantitative studies, 27 studies were designed or conducted in a way that minimised bias, nine studies were partly designed or conducted to minimise bias and had aspects of the study design that were unclear, and 13

Table 2
Included studies measuring knowledge of human papillomavirus (HPV) and head and neck cancer

Reference Country	Sample	Response rate	Study design	Outcomes/measures	Relevant findings
[45] Jordan	112 newly graduated medical and dental SHO level; 49% dental degree, 51% medical	Not reported	Survey (in person)	Knowledge of risk factors for oral cancer (e.g. Which of the following factors is considered an increased factor for oral cancer: Human papillomavirus as a response option)	- HPV correctly identified as a risk factor by 34% - more dental (47% versus 21%) than medical responded correctly
[46] USA	651 dental hygienists from North Carolina State Board of Dental Examiners	53%	Survey (postal)	Knowledge of risk factors for oral cancer (e.g. In the United States, which of the following factors places an individual at high risk for oral cancer? Human papillomavirus as yes/no/don't know option)	- 47.1% knew HPV a risk factor for oral cancer - 32% felt patients are knowledgeable about oral cancer risk factors
[47] * USA	609 men aged 18–59 years from population-based panel of US households; Men's Health Study	70%	Survey (online)	Awareness and knowledge (e.g. Which of the following do you think might increase the chances of getting oral cancer? Infection with a virus as a response option) Beliefs about causes of HPV-related disease (e.g. Do you think HPV can cause oral cancer? Yes/no/don't know) Knowledge of oral cancer risk factors	- More men knew HPV can cause genital warts (41%) than oral cancer (23%) - 43% identified infection with a virus as a potential cause of oral cancer (less than for anal cancer or genital warts) - Few believed sexual behaviours increases risk of oral cancer (23% having sex; 26% high number of sexual partners)
[48] USA	248 1st, 2nd, 3rd and 4th year dental students at University of Maryland Baltimore College of Dental Surgery	59.6%	Cross-sectional survey (in person and postal)	Knowledge of oral cancer risk factors	- 30.8% 1st year, 89.1% 2nd year, 78.1% 3rd year, 81.8% 4th year knew HPV is a risk factor for oral cancer
[49] USA	163 dental students, Medical University of South Carolina	79.1%	Survey (in person)	Knowledge of oral cancer risk factors	- 79.8% correctly identified HPV as a risk factor
[50] Canada	670 dentists, British Columbia and Nova Scotia	55.2%	Survey (postal)	Knowledge of oral cancer risk factors	- 53.1% correctly identified HPV as a risk factor for oral cancer
[51] Puerto Rico	206 Men in sexually transmitted disease clinic	Not reported	Survey (in person)	HPV awareness, HPV knowledge (e.g. HPV is associated with oral cancer: true/false/don't know)	- 27.4% knew HPV infection has a role in oral cancer

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Table 2 (continued)

Reference Country	Sample	Response rate	Study design	Outcomes/measures	Relevant findings
[52] USA	17 dentists in 2 focus groups; 21 dental hygienists in 2 focus groups	Not reported	Qualitative focus groups	Assess awareness of oral health providers regarding the HPV-oral cancer link Elicit attitudes and perceived role in screening for HPV-oral cancer lesions and discussing HPV as a contributing factor for oral cancer	- Participants ranged from a complete lack of knowledge to understanding some intricacies of the HPV-oral cancer link - Shifts in dentistry practice were seen as a result of the HPV-oral cancer link and there was a desire for additional guidance from professional organisation on ways to manage screening for HPV-related oral cancer - Discomfort was expressed in discussing the HPV-oral cancer link with patients, with concerns about the appropriateness of HPV-oral cancer discussions with patients due to confidentiality and gender roles - Responses varied as to whether it was their role to discuss with patients - 60% knew HPV is a risk factor for oral cancer
[53] Ireland	254 dentists	Not reported	Cross-sectional survey (online)	Knowledge of oral cancer risk factors	- 34% knew having HPV 'increases the risk of getting mouth or throat cancer'
[54] USA	93 community members	32%	Survey (telephone)	Knowledge of oral cancer risk factors	- Almost 54% identified HPV as a risk factor for oral cancer
[55] Romania	192 1st–6th year dental students; 139 female, 53 male	100%	Cross-sectional survey (in person)	Knowledge of oral cancer risk factors	
[56] USA	205 American Indian community members recruited via two community events; 70% female	Not reported	Survey (in person)	Knowledge of the risk factors of head and neck cancer including HPV (e.g. Do you think that HPV can cause head and neck cancer? yes/no/don't know)	- 32% had heard of head and neck cancer - 23% identified having multiple sexual partners as a risk factor - 36% thought HPV is related to head and neck cancer
[57] Jordan	330 primary healthcare professionals	87%	Survey (face-to-face interview)	Knowledge of oral cancer risk factors	- 43.3% identified Human papillomavirus as a risk factor
[58] † Germany	306 dentists in Schleswig-Holstein	14%	Survey (postal)	Knowledge of oral cancer risk factors (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- 57.8% identified Human papillomavirus as a risk factor
[59] Germany	394 dentists in Schleswig-Holstein	17%	Survey (postal)	Knowledge of oral cancer risk factors (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- 61.2% identified Human papillomavirus as a risk factor; 63.4% in those participating at re-evaluation and attending a continuing education course on oral cancer

[60] † Germany	306 dentists in Schleswig-Holstein; 1000 members of the public	14%	Survey (postal and telephone)	Knowledge of oral cancer risk factors (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- 57.8% of dentists and 29% of the public identified Human papillomavirus as a risk factor
[61] Germany	388 medical practitioners in Schleswig-Holstein	13%	Survey (postal)	Knowledge of oral cancer risk factors (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- Human papillomavirus recognised as risk factor by 70% otorhinolaryngology, 54% GPs, 50% internal medicine (continuing education for general medical care), 51% internal medicine, 82% dermatologists
[62] * USA	609 men; 312 gay and bisexual, 296 heterosexual	70%	Survey (online)	Knowledge of HPV (e.g. Do you think HPV can cause oral cancer? Yes/no/don't know)	- 21% of heterosexual men and 25% of gay/bisexual men knew HPV can cause oral cancer
[63] Saudi Arabia	236 healthcare professionals	Not reported	Cross-sectional survey	Knowledge of oral cancer risk factors	- 39.1% knew Human papillomavirus is a risk factor for oral cancer
[64] Saudi Arabia	167 undergraduate medical students (all students in years 4–6)	100%	Cross-sectional survey (in person)	Knowledge of oral cancer risk factors (e.g. Which of the following factors places an individual at high risk for oral cancers? Human papillomavirus as yes/no/don't know option)	- 65.7% overall identified Human papillomavirus as high-risk factor of oral cancer - Male 4th year 19%; 5th year 17%, 6th year 16% - Female 4th year 5%; 5th year 4%, 6th year 4%
[65] Saudi Arabia	479 undergraduate dental students (all students in years 4–6)	87.1%	Cross-sectional survey (in person)	Knowledge of oral cancer risk factors	- 83.7% identified Human papillomavirus as placing someone at high risk for oral cancer - Male 4th year 10%; 5th year 15%; 6th year 15% - Female 4th year 12%; 5th year 15%; 6th year 16% - 32.9% knew 'HPV infections can cause oral cancers' and 24.2% knew 'HPV infections can cause pharyngeal (throat) cancers'
[66] Canada	176 males at postsecondary institutions in Greater Vancouver	Not reported	Survey (in person)	Knowledge of HPV	- 68% considered themselves not very or not at all knowledgeable about head and neck cancer - Knowledge of HPV as a risk factor in 0.8% - 12.8% were aware of this association when specifically queried about the association between HPV and throat cancer
[67] USA	2126 US adults from Harris Interactive online panel	Not reported	Cross-sectional survey (online)	Awareness (e.g. Did you know that the virus HPV (human papillomavirus) that causes cervical cancer is also associated with throat cancer?) Knowledge (e.g. How knowledgeable are you about oral, head, and neck cancer? Likert scale not at all to extremely knowledgeable)	- Respondents with a college or university degree were more likely to associate HPV with throat cancer (14.8% versus 10%) - Older age was associated with less knowledge of HPV as a risk factor

(continued on next page)

Table 2 (continued)

Reference Country	Sample	Response rate	Study design	Outcomes/measures	Relevant findings
[68] USA	297 American Head and Neck Society head and neck surgeons	27.5%	Survey (online)	Assess clinical practices Assess attitudes Assess knowledge regarding HPV-related cancer of the head and neck	- 90.9% said they discuss HPV as a risk factor with patients - Respondents specifically with daughters - about 85% discussed HPV as a risk factor - Scored very well on knowledge items of HPV - in 5 out of 7, over 92% of responses were correct - 88% knew HPV is a risk factor for oral cancer
[69] USA	619 dentists in Maryland	53.6%	Survey (postal)	Knowledge of oral cancer risk factors	- 29.9% knew HPV definitely increases the risk of developing oral, head and neck cancer - Male 49%; Female 62.6%
[70] USA	303 drag racers (28.3%) and fans (70%), vendors (1.7%) attending annual United Black Drag Racers drag racing event in St Louis	Not reported	Survey (in person)	Knowledge of HPV and head and neck cancer (e.g. Please indicate whether you think that each of these things may or may not increase a person's chance of getting head and neck cancer: Human papillomavirus infection; certain types of HPV can lead to oral cancer; True)	
[71] USA	584 licensed dentists in North Carolina	52%	Survey (postal)	Knowledge of oral cancer risk factors (e.g. In the United States, which of the following factors places an individual at high risk for oral cancer? Human papillomavirus listed as an option)	- 60% aware of Human papillomavirus as a risk factor
[72] Italy	1000 lesbian, gay and bisexual men and women	86.8%	Cross-sectional survey (in person)	Know that HPV can cause oropharyngeal cancer	- 47% gay men, 44% lesbians, 31% bisexual men and 35% of bisexual women knew oral cancer is an HPV-related disease - The vast majority knew unprotected sex was the main risk factor - 60.6% had heard of HPV - 29.5% knew infection with HPV was a contributing factor for oral cancer - 61.4% overall knew HPV is associated with an increased risk for oral cancer; 33.7% 1st year; 58.7% 2nd year; 80.8% 3rd year; 64.7% 4th year - Human papillomavirus ranked as high risk by 26% dentists, 37% physicians; medium risk by 49% dentists and 45% physicians; low risk by 26% dentists, 37% physicians
[73] USA	62 senior citizens	66%	Survey (in person)	Knowledge of oral cancer risk factors	
[74] USA	450 medical students, South Carolina	78.8%	Cross-sectional survey (in person)	Knowledge of oral cancer risk factors	
[75] USA	269 dentists, 19 oral surgeons, 221 physicians	57% dentists 76% oral surgeons 45% physicians	Cross-sectional survey (postal)	Knowledge of oral cancer risk factors (e.g. Rank (high, medium, low) the association of known high-risk factors (Human papillomavirus) with oral cancer)	

[76] * USA	609 men aged 18–59 from national panel of US households	70%	Cross-sectional survey (online)	Knowledge of HPV (e.g. Do you think HPV can cause oral cancer? Yes/no/don't know)	- 21% of those having heard of HPV responded yes to HPV can cause oral cancer
[77] * USA	306 men self-identified as gay or bisexual aged 18–59 from national panel of US households	70%	Cross-sectional survey (online)	Knowledge of HPV (e.g. Do you think HPV can cause oral cancer? Yes/no/don't know)	- 25% of those having heard of HPV responded yes to HPV can cause oral cancer
[78] USA	2393 general population from rural areas	Not reported	Survey (telephone)	Knowledge of risk factors for mouth and throat cancer	- 40.2% Having Human papillomavirus "Yes-it increases the risk of getting mouth or throat cancer"
[79] Malaysia	362 dentists	41.7%	Survey (in person)	Knowledge of oral cancer risk factors	- 67.2% knew Human papillomavirus is a risk factor for oral cancer
[80] USA	267 parents of sons eligible to receive HPV vaccination	Not reported	Cross-sectional survey (in person)	Parents' knowledge of HPV in oropharyngeal cancer	- 18% knew role of HPV in oropharyngeal cancer
[81] Malaysia	147 final year medical and dental undergraduates of Universiti Sains Malaysia	73.5%	Survey (in person)	Aetiology of oral cancer	- 59.6% of medical students and 75.6% of dental students knew of role of HPV in aetiology of oral cancer (not statistically significant difference)
[82] USA	68 male African American college students, St Louis	Not reported	Cross-sectional survey (online)	Knowledge of HPV	- 60.2% knew HPV can cause oral cancer in men; 61.7% knew HPV can cause oral cancer in women
[83] USA	361 freshman students at Texas State University	10.7%	Survey (online)	Knowledge: - HPV can be contracted through oral sex - HPV has a strong correlation with oropharyngeal cancer - HPV is associated with some head and neck cancers	- 71.5% knew HPV could be contracted through oral sex - 51.6% knew of an association between HPV and oropharyngeal cancer - 18.2% knew HPV is associated with some head and neck cancers
[84] USA	179 men self-identified as gay and bisexual aged 18–29 from student organisations and social networking sites	Not reported	Survey (online)	Knowledge of HPV	- 25% of those having heard of HPV responded yes to HPV can cause oral cancer
[85] USA	491 NASCAR fans, 158 medical students, 186 undergraduate students	Not reported	Survey (in person)	Awareness of relationship between HPV and head and neck cancer (e.g. How much do you agree that HPV increases the risk of head and neck cancer?)	- Mean score: Medical students 2.84; Undergraduates 2.31; NASCAR 2.63

* These four papers used the data from one study.

† These two papers used the data from one study.

studies were either unclear on aspects of the study reported or may not have addressed all potential sources of bias. No studies were assessed as having significant sources of bias across all aspects of the study design. Most studies described the source population well, used reliable and valid outcome measures, measured outcomes that were relevant and used appropriate analytical methods. Of 25 studies in which it was relevant to carry out a power calculation, only eight did so. Many of the studies had small samples and so could not be generalised to the source population. For the two qualitative studies, both were clear in the purpose of the study, carried out the data collection appropriately, were clear on the context in which the study was carried out, conducted reliable analysis, provided convincing findings and drew relevant conclusions. Both studies were unclear about whether the relationship between the researcher and participants had been

considered. Both studies were considered to be designed to have minimised bias.

Discussion

This review is the first to draw together the emerging literature on the psychosocial implications of an HPV-related HNC diagnosis and awareness of the link between HPV and HNC. Quality of life was measured in the HPV-related HNC patient population, with inconsistent results found. Quality of life in those with HPV-positive HNC was found to be higher, lower or equivalent to those with HPV-negative HNC. In longitudinal studies, irrespective of the instrument used, quality of life in patients was at its lowest 2–3 months after diagnosis. In some studies, quality of life almost returned to baseline

Table 3
Scores from psychosocial measures in human papillomavirus (HPV)-related head and neck patients in nine* studies

Reference	Measure	HPV+	HPV–	Significant difference
[36]	Quality of life - EORTC QLQ-C30 (median score; scale range 0–100)			
	Emotional	91.67	83.33	NS
	Social	100	100	NS
	Global health	83.33	79.17	NS
[37]	Quality of life - HNCl (mean score; scale range 0–100)			
	Baseline	94	75	NS
	3 weeks	79	88	NS
	3 months	48	58	NS
	6 months	63	83	NS
	12 months	88	/	NS
[38]	Quality of life - HNCl (mean score; scale range 0–100)			
	12 months	75	78	NS
[40]	Quality of life - UWQOL (mean score across 12 domains; scale range 0–100)			
	Baseline	76	50	0.008
	2 months	57	51	NS
	6 months	67	59	0.034
	12 months	69	64	NS
	>12 months	82	65	0.013
[43]	Quality of life - UWQOL (mean score across 12 domains; scale range 0–100)			
	Pre-treatment	86	79	0.015
	Immediate post-treatment	63	73	NS
	Post-treatment	75	77	NS
[39]	Major depression	9%	10%	NS
	Anxiety disorder	6%	12%	NS
[42]	Distress (mean; scale range)	3.38 (0–9)	/	
	Self-blame (mean; scale range)	2.27 (1–4)	/	
[41]	EQ-5D (mean utility values)			
	Women	0.7	/	
	Men	0.8	/	
[44]	Quality of life - UWQOL (mean score; scale range 0–100)			
	Pre-treatment	10	/	
	24 months	15.2	/	
	Long term	16.5	/	
	HNQOL (mean score; scale range 0–100)			
	Pre-treatment	15.1	/	
	24 months	9.5	/	
	Long term	11.9	/	

EORTC, European Organization for Research and Treatment of Cancer; HNCl, Head and Neck Cancer Inventory; UWQOL, University of Washington Quality of Life; HNQOL, Head and Neck Quality of Life.

* One reference not included as used qualitative methodology [35].

Table 4

Knowledge about human papillomavirus (HPV) and oral cancer reported in 35* studies

Question	% (reference)	Sample population
Heard of HPV ... (closed question)	70.6% [47]	General population men (USA)
	61% [76]	General population men (USA)
	79% [77]	General population men (USA)
	93% [84]	General population men (USA)
	60.6% [72]	General population (Italy)
	59% [56]	General population (USA)
	80% [66]	College students (Canada)
	85% [82]	College students (USA)
HPV as a risk factor for oral cancer was known by ... (closed question)	53.1% [50]	Dentists (Canada)
	60% [71]	Dentists (USA)
	57.8% [58]	Dentists (Germany)
	26% [75]	Dentists (USA)
	61.2% [59]	Dentists (Germany)
	60% [53]	Dentists (Ireland)
	57.8% [60]	Dentists (Germany)
	88% [69]	Dentists (USA)
	67.2% [79]	Dentists (Malaysia)
	47.1% [46]	Dental hygienists (USA)
	79.8% [49]	Dental students (USA)
	66.5% [48]	Dental students (USA)
	54% [55]	Dental students (Romania)
	83.7% [65]	Dental students (Saudi Arabia)
	34% [45]	Newly graduated medical and dental personnel (Jordan)
	37% [75]	Physicians (USA)
	39.1% [63]	Healthcare professionals (Saudi Arabia)
	91% [68]	Head and neck surgeons (USA)
	50–82% [61]	Medical practitioners (Germany)
	43.3% [57]	Healthcare professionals (Jordan)
	61.4% [74]	Medical students (USA)
	65.7% [64]	Medical students (Saudi Arabia)
	44% [72]	General population (Italy)
	29% [60]	General population (Germany)
	32% [54]	General population (USA)
	40.2% [78]	General population (USA)
	0.8% [67]	General population (USA)
	29.5% [73]	General population (USA)
	29.9% [70]	General population (USA)
	18% [80]	General population (USA)
Knew HPV can cause oral cancer/ head and neck cancer	23.3% [47]	General population men (USA)
	21% [76]	General population (USA)
	25% [77]	General population (USA)
	39% [84]	General population men (USA)
	21–25% [62]	General population men (USA)
	27.4% [51]	General population men (Puerto Rico)
	36% [56]	General population (USA)
	12.8% [67]	General population (USA)
	18.2% [83]	College students (USA)
	59.6% [81]	Medical Students (Malaysia)
	75.6% [81]	Dental Students (Malaysia)
	32.9% [66]	College students (Canada)
	60.2% in men [82]	College students (USA)
	61.7% in women [82]	College students (USA)
Knew HPV is strongly associated with oropharyngeal cancer	51.6% [83]	College students (USA)

* Two references not included as the studies did not use comparable methodology [52,85].

levels after 12 months. The UWQOL was the instrument used in three of the 10 studies included in this review. This scale is specific to HNC and measures 12 different domains as single-item questions. To allow for

comparisons across studies, it would be ideal to have a well-validated, standardised measure that could be used in all studies. As previously reported, it is difficult to make generalised statements about quality of life that can aid in

clinical decision making, due to inconsistencies in the design of quality of life instruments for HNC and a lack of unified reporting standards [86].

Use of other psychosocial measures was limited, with only one other primary research study measuring domains other than quality of life. This one study found clinically meaningful levels of distress in 30% of patients, but relatively low levels of self-blame [42], suggesting there may be a need for interventions that may help alleviate distress levels. In the one qualitative study, a few survivors of HPV-positive HNC reported feelings of stigma and embarrassment about their diagnosis and this affected their sexual relationships, consistent with findings from the cervical cancer literature [24] and previous research with health professionals documenting concerns of HPV-positive HNC patients [87]. It is therefore difficult to draw conclusions based on the limited research that has been conducted around the psychosocial impact of HPV-related HNC. Future work is needed to explore the psychosocial impact of this diagnosis on the patient group, as well as their partners, the general population and health professionals.

The relationship between HPV and HNC is not well-known across most populations in the studies included here. The most knowledgeable group about HPV as a risk factor for HNC were second year dental students, dentists and head and neck surgeons (>85%), compared with one study finding that less than 1% of US adults knew that HPV is a risk factor for HNC. Awareness levels ranged across a variety of samples of the general population, dentists, students and specific sexually orientated groups, from 18 to 67%. Almost half the studies included dentists, dental hygienists or dental students, suggesting that the role dentists have to play in HPV and HNC is being increasingly recognised and educating them about HPV as a risk factor is important. All the questions were recognition questions rather than recall and so may not represent the true knowledge of participants as previous studies have found awareness to be higher in participants when responding to recognition questions when compared with recall [88,89]. One study assessing knowledge in medical practitioners in Ireland found that when asked to list the risk factors they would associate with oral cancer, HPV was not listed [90]. There was also no standardised question assessing knowledge of the link between HPV and HNC, some asking it as a risk factor, whereas others were more specific (e.g. HPV is associated with some head and neck cancers). None of these studies were conducted in the UK, so no conclusions can be drawn about the level of knowledge in the UK. These studies were mainly from the USA, indicating a wide range of knowledge across different population subgroups, but that generally, there is a need for greater awareness.

Strengths and Limitations

Adhering to PRISMA guidelines ensured this review was carried out systematically. By including quantitative and qualitative studies in the review, we avoided exclusion of any eligible and relevant studies. As a number of different

instruments were used to measure quality of life and at different points in the patient care continuum, it was difficult to compare across studies.

Conclusions

A limited number of studies have measured the psychosocial impact of a diagnosis of HPV-positive HNC and those few that have, have only measured this in patient populations. Future work is needed with the partners of HPV-positive HNC patients and health professionals caring for these patients. The limited knowledge of the association between HPV and HNC among the public also indicates the need for research to explore the information that these populations are receiving. The development of collaborations between behavioural scientists and clinicians in this field will help to ensure that awareness of the role of HPV in HNC is raised, and that the adverse psychological consequences associated with diagnosis are understood and minimised.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.clon.2016.02.012>.

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APPENDIX 4.2: SEARCH STRATEGY AND NUMBERS FROM EACH DATABASE

	MEDLINE, EMBASE, PsycINFO	Web of Science	CINAHL plus
Health condition of interest	Cancer combinations		
	1] "Head and Neck Neoplasms"/ 2] "Head and neck cancer".mp. 3] "Head and neck tumor\$.mp. 4] "Head and neck tumour\$.mp 5] Oropharyngeal Neoplasms/ 6] Oropharyngeal cancer\$.mp	(oropharyngeal cancer* OR oropharyngeal neoplas* OR head AND neck cancer* OR head AND neck tumor OR head AND neck tumour OR head AND neck neoplasms)	1] Oropharyngeal cancer* 2] "oropharyngeal neoplasms" 3] "head and neck cancer" 4] (MH "Head and Neck neoplasms") OR "head and neck neoplasms"
	HPV combinations		
	8] HPV.mp 9] Human papillomavirus.mp 10] Human papilloma virus.mp. 11] Papillomavirus Infections/	(hvp OR human papillomavirus OR human papilloma virus OR papillomavirus infections)	6] Hpv 7] Human papillomavirus 8] Human papilloma virus 9] Papillomavirus infections
Psychosocial outcomes of interest	13] Psych\$.mp. 14] Depression/ or depression.mp 15] Anxiety/ or anxiety.mp. 16] "Quality of life"/ or "quality of life.mp. 17] Psychosocial.mp	(psych* OR psychosocial OR depression OR anxiety OR "quality of life" OR knowledge)	11] Psych* 12] Psychosocial 13] MH Depression 14] MH Anxiety 15] MH Psychosocial aspects of Illness 16] MH Psychology 17] MH Quality of Life
Knowledge	18] Knowledge/ or knowledge.mp		18] (MH "knowledge") OR "knowledge"
Search combinations	1 or 2 or 3 or 4 or 5 or 6		1 or 2 or 3 or 4
	8 or 9 or 10 or 11		6 or 7 or 8 or 9
	13 or 14 or 15 or 16 or 17 or 18		11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
	7 and 12 and 19		5 and 10 and 19
Search results	PsycINFO 4 MEDLINE 131 EMBASE 223	WEB OF SCIENCE 393	CINAHL PLUS 31

APPENDIX 4.3: STUDY 1 - QUALITY ASSESSMENT FOR QUANTITATIVE STUDIES

Study identification		
Study Design		
Assessed by		
1. Is the source population or source area well described? - Was the country, setting, location, population demographics etc. adequately described?	++ + - NR NA	Comments:
2. Is the eligible population or area representative of the source population or area? - Was the recruitment of individuals, clusters or areas well defined? - Was the eligible population representative of the source? - Were important groups under-represented?	++ + - NR NA	Comments:
3. Do the selected participants or areas represent the eligible population or area? - Was the method of selection of participants from the eligible population well described? - What % of selected individuals or clusters agreed to participate? Were there any sources of bias? - Were the inclusion or exclusion criteria explicit and appropriate?	++ + - NR NA	Comments:
4. Were the outcomes measures reliable? - Were outcome measures subjective or objective? - How reliable were outcome measures? - Was there any indication that measures had been validated?	++ + - NR NA	Comments:
5. Were outcomes relevant? - Where surrogate outcome measures were used, did they measure what they set out to measure?	++ + - NR NA	Comments:
6. Was follow-up meaningful? - Was follow-up long enough to assess long-term benefits or harms? - Was it too long, e.g. participants lost to follow-up?	++ + - NR NA	Comments:
7. If there were more than one group, were these similar at baseline? If not, were these adjusted? - Were there any differences between groups in important confounders at baseline? - If so, were these adjusted for in the analyses - Were there likely to be any residual differences of relevance?	++ + - NR NA	Comments:
8. Was the study sufficiently powered? - Is the power calculation presented? If not, what is the expected effect size? Is the sample size adequate?	++ + - NR NA	Comments:
9. Were the analytical methods appropriate? - Were important differences in follow-up time and likely confounders adjusted for? - If a cluster design, were analyses of sample size and effect size performed on clusters? - Were sub group analyses pre-specified? - Mean, median, standard deviations or percentages are reported for the most important outcome measures?	++ + - NR NA	Comments:
10. Are the study results internally valid? - How well did the study minimise sources of bias? - Were there significant flaws in the study design?	++ + - NR NA	Comments:
11. Are the findings generalizable to the source population?	++	Comments:

- Are there sufficient details given about the study to determine if the findings are generalizable to the source population?	+	
	-	
	NR	
	NA	

<https://www.nice.org.uk/article/pmg4/chapter/Appendix-F-Quality-appraisal-checklist-quantitative-intervention-studies>

++	Indicates that for that particular aspect of the study design, the study has been designed or conducted in such a way as to minimise the risk of bias
+	Indicates that either the answer to the checklist question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that particular aspect of study design
-	Should be reserved for those aspects of the study design in which significant sources of bias may persist
NR	Should be reserved for those aspects in which the study under review fails to report how they have (or might have been considered)
NA	Should be reserved for those study design aspects that are not applicable given the study design under review (for example, allocation concealment would not be applicable for case control studies)

APPENDIX 4.4: STUDY 1 – QUALITY ASSESSMENT FOR QUALITATIVE STUDIES

Study identification		
Study Design		
Assessed by		
1. Is a qualitative approach appropriate? - Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? - Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not Sure	Comments:
2. Is the study clear in what it seeks to do? - Is the purpose of the study discussed – aims/objectives/research question/s? - Is the adequate/appropriate reference to the literature? - Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
3. How defensible/rigorous is the research design/methodology? - Is the design appropriate to the research question? - Is a rationale given for using a qualitative approach? - Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? - Is the selection of cases/sampling strategy theoretically justified?	Defensible Indefensible Not sure	Comments:
4. How well was the data collection carried out? - Are the data collection methods clearly described? - Were the appropriate data collected to address the research questions? - Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
5. Is the role of the researcher clearly described? - Has the relationship between the researcher and the participants been adequately described? - Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:
6. Is the context clearly described? - Are the characteristics of the participants and settings clearly defined? - Were observations made in a sufficient variety of circumstances? - Was context bias considered?	Clear Unclear Not sure	Comments:
7. Were the methods reliable? - Was data collected by more than one method? - Is there justification for triangulation, or for not triangulating? - Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
8. Is the data analysis sufficiently rigorous? - Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? - How systematic is the analysis, is the procedure reliable/dependable? - Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:
9. Is the data 'rich'? - How well are the contexts of the data described?	Rich Poor	Comments:

<ul style="list-style-type: none"> - Has the diversity of perspective and content been explored? - How well has the detail and depth been demonstrated? - Are responses compared and contrasted across groups/sites? 	Not sure/not reported	
10. Is the analysis reliable? <ul style="list-style-type: none"> - Did more than one researcher theme and code transcripts/data? - If so, how were differences resolved? - Did participants feedback on the transcripts/data if possible and relevant? - Were negative/discrepant results addressed or ignored? 	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing? <ul style="list-style-type: none"> - Are the findings clearly described? - Are the findings internally coherent? - Are extracts from the original data included? - Are the data appropriately referenced? - Is the reporting clear and coherent? 	Convincing Not convincing Not sure	Comments:
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	
13. Conclusions <ul style="list-style-type: none"> - How clear are the links between data, interpretation and conclusions? - Are the conclusions plausible and coherent? - Have alternative explanations been explored and discounted? - Does this enhance understanding of the research topic? - Are the implications of the research clearly defined? - Is there adequate discussion of any limitations encountered? 	Adequate Inadequate Not sure	
14. How clear and coherent is the reporting of ethics? <ul style="list-style-type: none"> - Have ethical issues been taken into consideration? - Are they adequately discussed e.g. do they address consent and anonymity? - Have the consequences of the research been considered i.e. raising expectations, changing behaviour? - Was the study approved by an ethics committee? 	Appropriate Inappropriate Not sure/not reported	

<https://www.nice.org.uk/article/pmg4/chapter/appendix-h-quality-appraisal-checklist-qualitative-studies>

++	All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter
+	Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
-	Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter

APPENDIX 4.5: STUDY 1 - EXAMPLE DATA EXTRACTION FORM

Psychological factors in human papillomavirus related head and neck cancers		
ID number (from Endnote)	1	
Review author ID	RD	
Title:		
Authors:		
Title assessed as suitable for inclusion (circle as appropriate)	YES	NO
Reason for inclusion or exclusion:		
Abstract assessed as suitable for inclusion? (circle as appropriate)	YES	NO
Reason for inclusion or exclusion:		
Full text assessed as suitable for inclusion? (circle as appropriate)	YES	NO
Reason for inclusion or exclusion:		
Participants		
HPV status determined? (circle as appropriate)	YES	NO
Total number		
Age range		
Gender		
Number of participants		
Co-morbidities		
Date of study		
Method		
Study design		
Participant identification method		
Recruitment method		
Data collection		
Outcomes measured		
Setting		
Analytic method		
Results		
Psychological measures used? (circle as appropriate)	YES	NO
Anxiety measured? (circle as appropriate)	YES	NO
If yes, give results		
Depression measured? (circle as appropriate)	YES	NO
If yes, give results		
Quality of life measured? (circle as appropriate)	YES	NO
If yes, give results		
Knowledge measured? (circle as appropriate)	YES	NO
If yes, give results		
Any other measures? (circle as appropriate)	YES	NO
If yes, give results		
Notes		

APPENDIX 5.1: STUDY 2 – PUBLISHED PAPER

Open Access

Research

BMJ Open Print and online newspaper coverage of the link between HPV and oral cancer in the UK: a mixed-methods study

Rachael H Dodd, Laura A V Marlow, Alice S Forster, Jo Waller

To cite: Dodd RH, Marlow LAV, Forster AS, *et al.* Print and online newspaper coverage of the link between HPV and oral cancer in the UK: a mixed-methods study. *BMJ Open* 2016;6:e008740. doi:10.1136/bmjopen-2015-008740

► Prepublication history for this paper is available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2015-008740>).

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ABSTRACT

Objectives: The role of human papillomavirus (HPV) in some oral cancers has been reported in the news press, though little is known about the content of these articles. This study aimed to examine how frequently the link between HPV and oral cancer has been reported in the news press and to examine the content of these articles.

Design: UK media articles were searched for articles relating to oral cancer and HPV in the database NexisUK. Of 854 articles identified by the initial search, 112 were eligible for inclusion (2002–2014) and content analysis was used to determine the main themes discussed.

Results: Themes included actor Michael Douglas' claim that his throat cancer was caused by HPV, the riskiness of oral sex, health information (including HPV as a cause of oral cancer) and the need to vaccinate boys against HPV. Many articles also referred to the link between HPV and cervical cancer and the increasing incidence of HPV-related oral cancer. The largest peak in articles occurred when Michael Douglas discussed his cancer (June 2013). Facts about HPV and references to research were provided in some articles.

Conclusions: The link between HPV and oral cancer and the transmission of HPV via oral sex was regularly discussed, yet coverage often lacked detailed health information. This could increase awareness of the link between oral sex and HPV risk, but may also lead to public concern about oral sex as a sexual behaviour.

INTRODUCTION

Traditional risk factors for oral cancer are tobacco and alcohol, but there is now overwhelming evidence that human papillomavirus (HPV) plays a causal role in some types of the disease.^{1–4} At least 25% of the estimated 85 000 oropharyngeal cancers diagnosed worldwide in 2008 were HPV-positive.⁵ HPV is a common sexually transmitted infection, with high-risk types shown to be responsible for up to 5% of all cancers worldwide, particularly cervical and other anogenital cancers.⁶ The main risk factors for

Strengths and limitations of this study

- This is the first study to examine the content of newspaper articles addressing the relationship between human papillomavirus (HPV) and some oral cancers.
- Using NexisUK to examine UK media coverage of the link between HPV and oral cancer provides a systematic analysis of a large number of publications.
- This study is limited to UK publications and to print and online media, so the results may not be representative of wider information available to the public.
- The articles in the study were only examined for content and not for accuracy of the information presented.

transmission of HPV are thought to be a greater number of sexual and (for oral infection) oral sex partners^{7–10} due to greater exposure to the virus.

Prior to the introduction of the HPV vaccination in 2008, public awareness of HPV (primarily in the context of cervical cancer) was measured in population-based studies to be between 25% and 50%.^{11 12} The HPV vaccination attracted a lot of media attention¹³ and knowledge of HPV appears to have increased following its introduction.¹⁴ In an online survey across the UK, USA and Australia following the introduction of the HPV vaccine, 39% of men and 62% of women in the UK reported having heard of HPV.¹⁵

In the oral cancer context, no UK studies have yet examined knowledge that HPV is a risk factor for oral cancer. In the USA, dental hygienists in North Carolina were found to have low knowledge of HPV as a risk factor for oral cancer compared with tobacco and alcohol.¹⁶ In a USA population-based online survey, HPV was recognised as a common risk factor for mouth and throat cancer by fewer than 1% of participants, and even when prompted explicitly about the link, just 13% said they had heard of



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the association.¹⁷ In an internet survey of men, a greater proportion linked HPV with genital warts than with oral cancer, with 43% identifying infection with HPV as a potential cause of oral cancer.¹⁸ Public awareness of the signs and risk factors for head and neck cancer has also been shown to be poor^{19–21} and the majority of oral cancers are diagnosed at an advanced stage.²²

As the media has been shown to influence people's beliefs²³ and is considered a major source of health information for many,²⁴ it is possible that media coverage of the link between HPV and oral cancer may influence public awareness and perceptions. The British media is no stranger to reporting stories about people in the public eye with cancer, most notably the stories of Jade Goody (an English reality television personality), Kylie Minogue (an Australian singer/songwriter) and Angelina Jolie (an American actress). Metcalfe *et al*²⁵ reported that an increased public interest in disease prevention can follow a celebrity diagnosis. In the UK, the case of Jade Goody (who died of cervical cancer) was associated with an increase in the number of women attending cervical screening.²⁶ In 2013, American actor Michael Douglas disclosed in an interview with *The Guardian* newspaper that his throat cancer was 'caused by HPV which actually comes about from cunnilingus'. This disclosure received global attention, giving the media an opportunity to discuss the link between HPV and oral cancer. However, media reports are sometimes criticised for the lack of detail they provide, for example, with the announcement of Angelina Jolie's double mastectomy many failed to give information about the rarity of her condition.²⁷

Media priming may be used to strengthen the association between a person's existing beliefs and their subsequent behaviour by making these beliefs more accessible.²⁸ Mass media campaigns for cancers such as breast and lung (eg, the Cancer Research UK Be Clear on Cancer campaign) have been shown to be effective in increasing awareness of key symptoms for these cancers and increases in general practitioner attendance.²⁹ As this shows, media coverage is one route through which public understanding of health issues might be improved, but little is known about British media coverage of the link between HPV and oral cancer. The media has been shown to be a common source of information about HPV¹² and greatly influences public opinion, and as such it is crucial to examine how the link is portrayed by the British media. As the media may play an important role in fulfilling the information needs of the public, examining the content of articles will establish what information is being conveyed and how this is communicated. This study aimed to examine how frequently the link between HPV and oral cancer has been reported in the news press and whether this has changed over time. The study also aimed to examine the content of the articles, in particular looking at the main topics

reported and how the link between HPV and oral cancer has been presented.

METHODS

The NexisUK database was used to search for print and online articles in the UK relating to HPV and oral cancer. NexisUK is an online database providing full-text access to international, national and regional news sources, and is updated daily. The search was conducted on the 20 August 2014 with no date limits applied. The search terms 'oral cancer', 'mouth cancer', 'throat cancer', 'oropharyngeal cancer', 'head and neck cancer' were entered into the database separately, limited to major mentions (in the headline, lead paragraph or indexing) and combined with (HPV OR human papillomavirus) within UK publications. Newswire and non-business news publications (eg, obituaries, sports) were not searched. The full text of each publication was reviewed by RHD. Newspaper articles were categorised using Newsworks³⁰ as 'broadsheet' newspapers (more intellectual in content eg, *The Guardian*, *The Times*), 'middle market' newspapers (coverage of entertainment and important news stories eg, *Sunday Express*, *London Evening Standard*) and 'tabloid newspapers' (reporting mostly on sensational material, eg, *The Sun*, *Kidderminster Shuttle*). Regional newspapers were categorised by discussion.

Quantitative analysis—frequency of articles

The frequency of reporting of the link between HPV and oral cancer was analysed using a frequency count. The number of articles per month reporting the link was plotted from the first publication to the most recent publication.

Qualitative analysis—content of the articles

The headlines of all articles were analysed descriptively. The content of eligible articles was analysed using Framework Analysis.³¹ RHD first familiarised herself with the content by reading through all the eligible articles, making notes of recurring themes and summarising each article. Using the qualitative package NVivo V.10, a list of codes was generated from the data and these codes were applied to the data. The data were summarised and organised into a matrix of main themes and subthemes, with each row representing an article and each column representing a theme/subtheme. ASF coded 20% of the articles to test inter-rater reliability. Second coding of 20% of the articles has been considered sufficient in similar studies.^{32–33} Cohen's κ across all themes was 0.71 representing a substantial agreement.^{34–35} Table 1 shows Cohen's κ for each main theme and subthemes. Any disagreements were resolved by discussion and the remaining articles were coded by RHD alone. Short quotations illustrating each theme are presented in the text, and additional quotes are presented



Table 1 Main themes and subthemes with inter-rater reliability

Theme	(Cohen's κ)	Description of theme
Michael Douglas' disclosure	(0.67)	The disclosure from Michael Douglas that his throat cancer was caused by HPV
Health information	(0.70)	Represents information communicated about HPV and oral cancer related to health. The subthemes represent specific health information given about HPV and oral cancer
A. HPV as cause of oral cancer	(0.73)	
B. Incidence of oral cancer	(0.61)	
C. Information about HPV	(0.62)	
1. Cause of cervical cancer		
2. How common HPV is		
3. Number of different types of HPV		
4. Demographic changes		
D. Better prognosis and survival	(0.79)	
E. Diagnosis and treatment for oral cancer	(0.77)	
F. Symptoms and screening for oral cancer	(0.56)	
G. Cited research evidence	(0.69)	
Riskiness of oral sex	(0.77)	Represents information communicated about the recognition of oral sex in the cause of oral cancer and how changes in sexual practice are thought to account for this
Vaccination of boys	(0.85)	Represents the calls for boys to be vaccinated in light of the evidence that HPV does not only cause oral cancer, but other cancers as well

HPV, human papillomavirus.

in table 2, along with the publication title, date published and quotation number.

RESULTS

Article characteristics

A total of 854 UK articles were identified. Articles were excluded if they were (1) duplicates (articles published around the same time, with the same number of words in the same publication and duplicating text) ($n=477$); (2) were published in a specialist magazine or publication ($n=80$); or (3) did not mention the link between oral cancer and HPV ($n=32$). Following these exclusions, 265 articles were eligible for inclusion in the quantitative analysis. An additional 153 articles were excluded from the qualitative analysis because they included fewer than 100 words about the link between oral cancer and HPV. These articles tended to include a sentence about the link between HPV and oral cancer as part of a story with a different focus; they did not have sufficient text to merit qualitative analysis. Overall 112 articles were suitable for the qualitative analysis.

The newspapers with the greatest number of articles eligible for qualitative analysis were The Times ($n=16$), MailOnline ($n=10$), The Guardian ($n=8$) and The Independent ($n=9$). Broadsheet newspapers accounted for 54% of the articles, 21% were from middle market newspapers and 25% were from tabloid newspapers. With regard to average length, broadsheet articles tended to be longer (530 words average), followed by those in middle market newspapers (472 words average), with tabloid newspapers having the shortest

(458 words average) articles. A fairly small proportion of articles (18/112; 16%) were published in regional papers.

Quantitative analysis—frequency of articles

No UK publications reported the link between HPV and oral cancer prior to 2001. Figure 1 shows the frequency of articles published per month mentioning the link between HPV and oral cancer. There was a steady number of articles reporting on the link, but for most years, on average, fewer than two articles were published per month across the newspapers. The largest number of articles reporting on the link between HPV and oral cancer was seen in 2013 (112/265). Broadsheet newspapers first reported that there was a link between HPV and oral cancer in October 2001, followed by tabloid newspapers in February 2004 and middle market newspapers in November 2009.

There was a noticeable peak in June 2013 (45/265) with 34/45 of these discussing Michael Douglas' throat cancer being caused by HPV. There were a few small peaks in articles published in May 2007 (6/265), with 5/6 discussing a research paper which further demonstrated the link between oral sex and throat cancer,⁷ in March 2012 (7/265) reflecting the publication of figures demonstrating a rise in mouth cancers, and in November 2013 (16/265) with 10/16 articles reflecting on mouth cancer awareness month.

Qualitative analysis—content of the articles

Headlines

About one-third (35/112) of the headlines mentioned oral sex (eg, 'Oral sex can lead to mouth cancer')

Table 2 Quotes from themes and subthemes

Quote (Q) number	Quotes	Themes	Newspaper information
1	'Michael Douglas did not say cunnilingus was the cause of his cancer. It was discussed that oral sex is a suspected cause of certain oral cancers...but he did not say it was the specific cause of his personal cancer.'	Michael Douglas' disclosure	<i>MailOnline</i> , 4 June 2013
2	'Even with statements from his publicist denying he had put the blame on oral sex specifically, this genie is not going back in the bottle. And perhaps that's a good thing.'	Michael Douglas' disclosure	<i>The Telegraph</i> , 4 June 2013
3	'Oral sex can lead to mouth cancer, according to new research.'	Riskiness of oral sex	<i>Birmingham Post</i> , 26 February 2004
4	'What is most strongly linked to oral HPV infection is the number of sexual partners someone has had in their lifetimes, in particular the number of individuals on whom they have performed oral sex.'	Riskiness of oral sex	<i>The Guardian</i> , 21 February 2011
5	'A US study showed about 10 per cent of men aged 14 to 69 have an oral HPV infection, compared with 3.6 per cent of women. Because HPV-related oral cancer is twice as common in men as in women, cunnilingus is considered riskier than fellatio.'	Riskiness of oral sex	<i>London Evening Standard</i> , 4 June 2013
6	'Without wanting to get too specific, this particular cancer is caused by HPV, which actually comes about from cunnilingus...But yeah, it's a sexually transmitted disease that causes cancer. And if you have it, cunnilingus is also the best cure for it.'	Riskiness of oral sex	<i>The Times</i> , 5 June 2013
7	'If you have an ulcer that doesn't heal after three weeks, see your dentist or doctor.'	Health information: symptoms	<i>Daily Mirror</i> , 28 March 2008
8	'Just a few strains cause problems, but one in particular, HPV-16, is known to cause cell changes which could develop into cancer.'	Health information: information about HPV	<i>MailOnline</i> , 16 March 2012
9	'Given that subgroups of people with HPV-related H&N [head and neck] cancers display excellent survival, these patients may in future be offered less aggressive treatment...'	Health information: diagnosis and treatment	<i>The Western Mail</i> , 25 February 2013
10	'Men are advised to check their neck for lumps when shaving and both sexes to look at the back of their throat while brushing their teeth.'	Health information: symptoms	<i>MailOnline</i> , 13 November 2013
11	'HPV is really, really common—to the point that if you're a sexually active adult, you've probably had it. By the age of 25, 90% of sexually active people will have been exposed to some form of genital HPV.'	Health information: the high prevalence of HPV	<i>The Guardian</i> , 2 June 2013
12	'Increased recovery rates among this kind of cancer sufferer. This would help explain why Douglas was given an 80% chance of survival, despite the advanced stage of his illness.'	Health information: better prognosis and survival	<i>The Guardian</i> , 2 June 2013
13	'In Britain, the number of mouth and throat cancers have increased by 40 per cent in just a decade.'	Health information: the incidence of oral cancer	<i>MailOnline</i> , 3 June 2013
14	'Treatments such as chemotherapy, radiotherapy and surgery are often more successful in mouth and throat cancers caused by the virus than those caused by tobacco and alcohol.'	Health information: better prognosis and survival	<i>MailOnline</i> , 16 July 2013
15	'These striking results provide some evidence that HPV16 infection may be a significant cause of oropharyngeal cancer.'	Health information: HPV causes oral cancer	<i>The Times</i> , 26 July 2013
16	'Mouth cancer survival rates of about 50% haven't changed in decades, but if the disease is caught early patients can have a 90% chance of a cure.'	Health information: diagnosis and treatment	<i>Daily Mirror</i> , 28 February 2014
17	<i>Professor Maura Gillison</i> —'The time has come to have a more thorough discussion about the potential benefits of HPV vaccines in boys ... When my patients ask whether they should vaccinate their sons [with the HPV vaccine], I say 'certainly'. The vaccine will protect them against genital warts and anal cancer and—as a potential by-product of that—it may protect them against oral cancer caused by HPV ... The time has come to consider offering the HPV vaccine to boys.'	HPV vaccination for boys	<i>The Independent</i> , 21 February 2011

Continued

Table 2 Continued

Quote (Q) number	Quotes	Themes	Newspaper information
18	Professor Margaret Stanley—'it is not ethical, fair or socially responsible to have a public-health policy that forces men to rely on herd immunity, which won't be reached for decades.'	HPV vaccination for boys	<i>MailOnline</i> , 3 June 2013
19	'We [Department of Health] recognise that the current vaccination programme does not offer protection against HPV-related cancers for gay men.'	HPV vaccination for boys	<i>The Independent</i> , 2 February 2014
20	'Campaigners are calling for boys to have the jab too in order to stem the "catastrophic rise" in cancers.'	HPV vaccination for boys	<i>Daily Mirror</i> , 28 February 2014

To avoid repetition, none of the quotes included in the text are included in the table.

Birmingham Post, 26 February 2004) and Michael Douglas was mentioned in a quarter (28/112) of the headlines (eg, 'Michael Douglas says cunnilingus gives you cancer but is he right?' *The Guardian*, 2 June 2013). 'Throat cancer' was the most frequently used term for the disease, mostly reflecting the terminology used by Douglas himself, with 'mouth cancer' and 'oral cancer' also used. Some headlines (33/112; 29%) emphasised the risk of oral sex and cancer (eg, 'Mouth cancer rise in young people is linked to oral sex' *The Metro*, 16 March 2012), and some used the words 'risk', 'alert' and 'dangers' when referring to the link between HPV and oral cancer:

Your life: Oral Sex cancer risk. (*Daily Mirror*, 28 March 2010)

Early alert for throat cancer. (*The Times*, 22 July 2013)

Stay alive to the dangers of mouth cancer. (*Kidderminster Shuttle*, 6 November 2010)

Others emphasised the sexual nature of the link using terms like 'sex virus', 'will oral sex ever feel safe again' and 'struck a blow for oral sex'.

Article content

Four main themes emerged from the content analysis of the reviewed articles: Michael Douglas' disclosure, the riskiness of oral sex, health information communicated about HPV, including HPV as a cause of oral cancer and its incidence, and the need to vaccinate boys against HPV.

Michael Douglas' disclosure

In June 2013, Michael Douglas revealed that HPV was responsible for his throat cancer and that it was transmitted through oral sex. This disclosure was more commonly reported in broadsheet newspapers. There was a peak in the number of articles covering this link (34/112; 30%) in June 2013, including those which reported on Michael

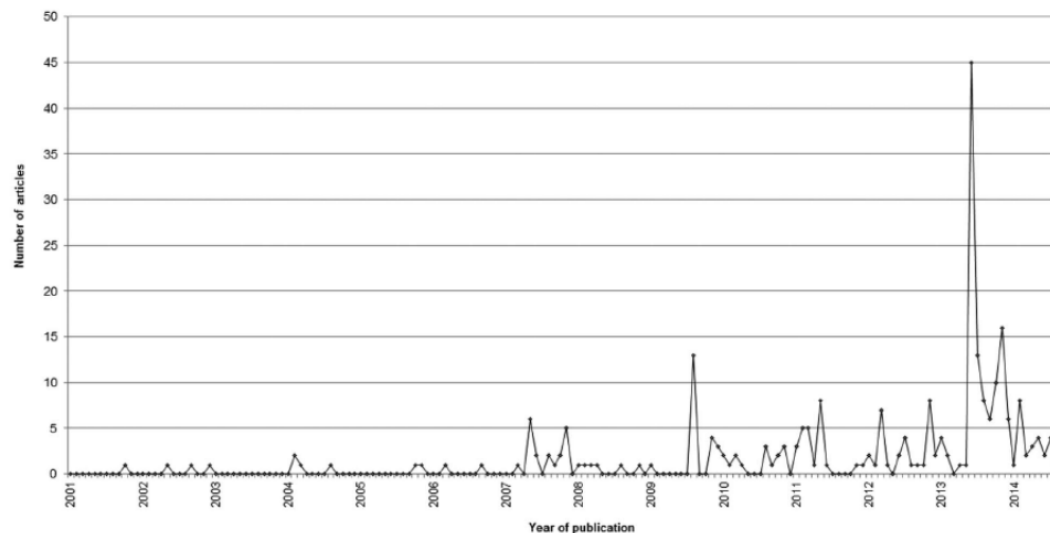


Figure 1 The number of UK media articles reporting on the link between oral cancer and human papillomavirus from 2001 to 2014.

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Douglas' subsequent assertion that he was talking about causes of oral cancer more generally, rather than being specific to him (*MailOnline*, 4 June 2013, Q1).

There were suggestions in some of the articles that Michael Douglas had raised awareness of the link between HPV and oral cancer and had 'broken the last taboo for men' by raising the topic of oral sex (*The Telegraph*, 4 June 2013, Q2).

Riskiness of oral sex

A large number (83/112; 74%) of the articles mentioned oral sex as a cause of mouth cancer (*Birmingham Post*, 26 February 2004, Q3).

HPV was mentioned as being transmitted through oral sex, with articles quoting Michael Douglas including the term 'cunnilingus' and stating that HPV is a sexually transmitted disease (*The Times*, 5 June 2013, Q6).

This disclosure from Michael Douglas led some articles to discuss the risk of different sexual behaviours, for example, 'Is cunnilingus inherently riskier than fellatio?' (*The Guardian*, 2 June 2013) with a number of these providing research findings (*London Evening Standard*, 4 June 2013, Q5).

Some articles (14/112; 13%) expressed the belief that the rise in throat cancer was due to changes in sexual practice: 'the rise in HPV-related throat cancer is being seen as the legacy of the sexual revolution that began in the 1960s' (*The Independent*, 21 January 2012), with an increase in oral sex practices leading to increases in oral HPV and therefore throat cancer (*The Guardian*, 21 February 2011, Q4).

The link between oral sex and mouth cancer was not as clear cut, according to Cancer Research UK quoted to have said 'it was unclear if it was linked with oral sex' (*The Independent*, 16 March 2012). A few (5/112; 4%) of the articles suggested that HPV transmitted through oral sex 'could overtake tobacco and alcohol as the main risk

factor in the next decade' (*Western Morning News*, 23 November 2010).

It was also acknowledged that 'oral sex is a topic which could not have been discussed openly even recently' (*The Telegraph*, 4 June 2013).

One article asked 'should oral sex be off the agenda' (*Daily Mirror*, 28 February 2014), with other articles terming oral sex as 'now officially life-threatening' (*The Times*, 26 May 2007) and that HPV is a 'devastating virus' (*The Sun*, 13 February 2014).

Health information

Most of the articles providing health information focused on the link between HPV and oral cancer. Table 3 shows what health information was presented in each type of publication. The different types of information are discussed below.

HPV causes oral cancer: As mentioning the link between HPV and oral cancer was an inclusion criteria, all articles included this, with the majority (88/112; 79%) of the articles mentioning the link between HPV and oral cancer within the first 100 words. The terms used were inconsistent, with mouth cancer, oral cancer and throat cancer used interchangeably. Some articles were more specific about the type of cancer caused (*The Times*, 26 July 2013, Q15).

The incidence of oral cancer: In total, 61/112 (54%) articles reported on the incidence of oral cancer, with 57/112 (51%) reporting that the number of cases was increasing. One newspaper quoted a Cancer Research UK expert as describing 'an emerging epidemic' (in oral cancer) and 5/112 (4%) quoted Cancer Research UK as linking the HPV virus to the 'rapid rise' (in oral cancer cases; *MailOnline*, 3 June 2013, Q13).

A change in the demographic characteristics of those being diagnosed with oral cancer was also mentioned in a number of the articles (49/112; 44%), emphasising

Table 3 Themes mentioned in articles across the publication types

Theme	Number of articles including each theme			
	All publications (n=112)	Broadsheet (n=61)	Middle market (n=23)	Tabloid (n=28)
Michael Douglas' disclosure	50 (45%)	25 (41%)	14 (61%)	11 (39%)
Health information				
Link oral cancer and HPV	112 (100%)	61 (100%)	23 (100%)	28 (100%)
Incidence of oral cancer	61 (54%)	29 (48%)	13 (57%)	19 (68%)
Information about HPV				
Cause of cervical cancer	63 (56%)	33 (54%)	12 (52%)	18 (64%)
100 variants of HPV	11 (10%)	5 (8%)	3 (13%)	3 (11%)
8/10 will contract HPV	12 (11%)	5 (8%)	3 (13%)	4 (14%)
90% will contract HPV by age 25	6 (5%)	6 (10%)	0	0
Better prognosis and survival	18 (16%)	4 (7%)	10 (43%)	4 (14%)
Diagnosis and treatment	29 (26%)	10 (16%)	10 (43%)	9 (32%)
Symptoms and screening	36 (32%)	15 (25%)	10 (43%)	11 (39%)
Riskiness of oral sex	83 (74%)	42 (69%)	20 (87%)	21 (75%)
Vaccination of boys	40 (36%)	22 (36%)	6 (26%)	12 (43%)

HPV, human papillomavirus.

that patients are increasingly younger, male, non-smokers and from professional backgrounds. A few (9/112; 8%) articles also suggested that there was a shift towards more women getting oral cancer.

Information about HPV: Over half of the articles also mentioned HPV as a cause of cervical cancer (63/112; 56%) and presented information about there being 'more than 100 variants' of HPV. In total, 19/112 (17%) articles highlighted that not all types of HPV cause cancer (*MailOnline*, 16 March 2012, Q8).

The high prevalence of HPV: In 30/112 (27%) articles, it was mentioned that most people will be infected with HPV at some point (*The Guardian*, 2 June 2013, Q11).

A total of 16/112 (14%) articles expressed the need for increased awareness of the link between HPV and oral cancer; for example, 'few people can recognise its symptoms' (*Kidderminster Shuttle*, 6 November 2010). Nigel Carter, Chief Executive of the British Dental Health Foundation was quoted as saying, 'there is a clear gap in public knowledge about what causes mouth cancer' (*Daily Mirror*, 28 February 2014).

Better prognosis and survival: The positive prognosis and survival rates of HPV-related oral cancer were discussed (18/112; 16%), sometimes in the context of Michael Douglas' own survival (*The Guardian*, 2 June 2013, Q12).

Survival was also discussed in comparison to oral cancers without HPV as a cause (*MailOnline*, 16 July 2013, Q14).

Diagnosis and treatment: Early diagnosis of oral cancer was mentioned as giving a 'better chance of successful treatment' (*Daily Mirror*, 28 February 2014, Q16) by 14/112 (13%) articles.

Treatment methods, particularly chemotherapy and radiotherapy were mentioned, as well as the possibility for less invasive treatment in the future (*The Western Mail*, 25 February 2013, Q9).

Symptoms: Symptoms of oral cancer were reported more frequently in tabloids and middle market newspapers than in broadsheets (*Daily Mirror*, 28 March 2008, Q7).

The importance of dentists was emphasised, explaining that they play a vital role in oral cancer diagnosis as well as doctors. Advice was given as a slogan, 'If in doubt, get checked out' and ways to look for symptoms of oral cancer were suggested (*MailOnline*, 13 November 2013, Q10).

Case studies were also included and often illustrated the symptoms of HPV-related oral cancer, the invasive and challenging treatment involved, and the importance of regular dental check-ups.

Cited research: Fewer than half (42/112; 38%) referred to research findings from peer-reviewed journals. Research that was cited included studies showing the increase in incidence and burden of HPV-related oral cancer, showing evidence for patients with oropharyngeal cancer carrying antibodies to the E6 protein from the HPV16 virus³⁶ and evidence for number of oral sex partners as a risk factor for HPV.⁷

HPV vaccination for boys

The link between oral sex and oral cancer was given as a strong reason for boys to be vaccinated against HPV. HPV Action, a group campaigning for the vaccination of boys, was mentioned in three articles. Many of the articles covering news of campaigns to vaccinate boys spoke of the opportunity for the vaccine to reduce the number of oral cancer cases in men, calling for it to be 'a gender neutral vaccination' (*Daily Mirror*, 28 February 2014, Q20).

Arguments were made about the cost-effectiveness of introducing the vaccine for boys (5/112; 4%) and that 'the Government could save thousands of lives and hundreds of millions of pounds for the NHS by vaccinating boys against a cancer-causing virus at a cost of around £20m a year' (*The Independent*, 2 February 2014).

An argument for vaccinating boys against HPV was also made with reference to other countries as Professor John Ashton said, 'It makes sense to give teenage boys as well as girls the HPV vaccine, which is already happening in Australia' (*The Guardian*, 19 September 2013).

Men who have sex with men were also acknowledged as an unprotected group in a number of articles (7/112 (6%); *The Independent*, 2 February 2014, Q19).

It was acknowledged that the HPV vaccination would have to be repositioned, as parents currently know it as 'the cervical cancer vaccine'. There was also recognition that oral cancer is not the only HPV-related cancer to affect boys and that the virus is linked to anal and penile cancers.

Experts were quoted as being in favour of HPV vaccination for boys, including Professor Maura Gillison, who published evidence of the link between HPV and oral cancer (*The Independent*, 21 February 2011, Q17; *MailOnline*, 3 June 2013, Q18).

Jamie Rae of The Throat Cancer Foundation and HPV Action, expressed the view that not vaccinating boys is 'inequitable—in fact, I'd say it's an infringement of human rights, for all boys' (*The Independent*, 2 February 2014) and it is 'a flawed and discriminatory policy' (*The Herald (Glasgow)*, 12 June 2013), in the campaign to vaccinate boys against HPV.

DISCUSSION

This study is the first to analyse print and online newspaper coverage of the link between HPV and oral cancer in the UK. Coverage of the link between HPV and oral cancer has increased in response to major news stories. Articles reporting the link between HPV and oral cancer increased in March 2012 as figures showed oral cancer cases to be rising. Michael Douglas' disclosure in June 2013 sparked an increase in media interest as well as discussions about vaccinating boys. The main themes found to be reported in UK publications were Michael Douglas' disclosure, the riskiness of oral sex, health information including HPV as a cause of oral cancer and its incidence, and the need to vaccinate boys against HPV.

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All the articles tended to report similar content and the themes remained consistent across the types of publication (eg, broadsheet or tabloid), but how this was presented did differ across publication type. Broadsheets were the first type of publication to report on the link in October 2001, followed by tabloids in February 2004 and middle market in November 2009. Results from research were reported in fewer than half of the articles. Basic facts about HPV were not reported in all articles, indicating that the public does not always receive even basic information which could help relieve any anxieties.

Articles focusing on Michael Douglas' disclosure were more likely to appear in broadsheets than the other types of publication, which is probably due to the interview being conducted with a *Guardian* reporter. Previous research has suggested that events such as a celebrity cancer diagnosis can create news coverage substantial enough to influence health behaviours such as attending cancer screening.^{26–37} Oral sex was said to be the cause of Michael Douglas' cancer in articles talking about his disclosure, but there were not many articles addressing what HPV is and the risk factors associated with it. There was a missed opportunity to educate the public as many articles did not discuss the signs and symptoms of oral cancer and what individuals should do if they find a symptom. Tabloid and middle market newspapers covered these more often than broadsheet newspapers, but only tabloid newspapers mentioned HPV in their coverage on Mouth Cancer Awareness Month, held in November every year. As different newspapers appeal to different reader demographics, it is important for communication of HPV and oral cancer to be consistent across all newspaper types to minimise inequalities in awareness and consequently health outcomes.

Many of the references to oral sex related to the transmission of HPV. Some of the articles placed emphasis on the risk of oral sex, reporting that those with HPV-related oral cancer are 'more likely to be connoisseurs of cunnilingus and fellatio'. These comments risk HPV-related oral cancer being seen as a sign of promiscuity and sensationalise it rather than including facts and presenting an HPV infection as common. This, in addition to the information on the rising incidence of HPV-related oral cancer, could lead the public to overestimate the prevalence of HPV-related oral cancer. In a study with health professionals, normalising HPV by emphasising its high prevalence and association with normal sexual behaviour was seen as a key message for patients, to try to minimise any possible negative psychological outcomes.³⁸ This information is also important for the partners of those diagnosed; we found that some articles suggested Michael Douglas could have contracted HPV from his wife, Catherine Zeta-Jones, and could suggest that she was to blame.

As Michael Douglas affirmed that he was talking about causes of oral cancer more generally, rather than being specific to him, this could also cause stigma towards

HPV-related oral cancer, as the public may feel that he was ashamed to admit his throat cancer was caused by oral sex. There is also the concern that those who have been diagnosed with HPV-related oral cancer will feel stigmatised, so it is important that appropriate messages are being given about HPV to reduce the stigma associated with this sexually transmitted infection.³⁹ Including case studies may help the public empathise with the person in the case study and reduce stigma. However, case studies reported in the articles were used to illustrate some of the symptoms for HPV-related oral cancer and how invasive and challenging the treatment can be. Endorsements from case studies where symptoms were noticed and highlighting good prognosis with early diagnosis may encourage the public to adopt health protective behaviours such as checking for lumps and attending the dentist regularly.

Articles which included reasons for vaccinating boys used case studies, Michael Douglas and research to support their campaigns. The media has been shown to increase knowledge of HPV after coverage of the introduction of the HPV vaccination.¹⁴ Media coverage of the campaigns and the connection to Michael Douglas' disclosure has the opportunity to raise awareness among parents and as all the articles took a positive stance towards vaccinating boys, this may influence parents' decisions about vaccinating their sons against HPV. Including endorsements from leading researchers in the field of HPV and oral cancer may have enhanced the credibility of messages in the articles and encourage parents to vaccinate their boys should they have the opportunity. Parents of boys will need to be able to communicate to their sons the link between HPV and sex, given that the vaccine is currently positioned as the 'cervical cancer vaccine'. The media could play a role in facilitating this.

This study is limited to UK publications and to print and online media, with broadcasts on television not examined, and so the results may not be representative of wider information available to the public. Different content may have been presented in television broadcasts which have not been picked up in this study. The articles in the study were only examined for content and not for accuracy of the information presented as this was not an aim of the study.

Examining responses to articles presenting the link between HPV and oral cancer through analysis of the discourse of online comments made on these articles would be an interesting area for future research. Coding the frequency of the stories in each article may also be useful to do in the future to understand which stories gain traction in the media. Assessing public knowledge about the link between HPV and oral cancer would also be useful, and an important first step towards raising public awareness and designing appropriate information for patients diagnosed with the disease.

In conclusion, this study is the first to show that the link between HPV and oral cancer has received coverage

in the UK media, but an opportunity was missed to educate the public and influence health behaviours, through the disclosure of Michael Douglas. It is important for researchers not only to monitor media coverage of the link, but to work with journalists to ensure the content of articles is accurate and appropriate. Transmission of HPV via oral sex was regularly discussed along with the link between HPV and oral cancer, which could raise public anxieties about oral sex. It is therefore important for journalists to aim to minimise stigma and blame associated with these messages, normalising HPV and portraying it as associated with normal sexual behaviour.

Contributors RHD, LAVM and JW conceived of the study and participated in the design. RHD participated in the acquisition, analysis and interpretation of the data and drafting of the manuscript. ASF also participated in the analysis and interpretation of the data. All the authors participated in the critical revision of the manuscript and approved the final version.

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APPENDIX 5.2: STUDY 2 - FRAMEWORK**Michael Douglas' disclosure**

1. HPV Sexually transmitted
2. Awareness
3. Transmission of HPV

Riskiness of oral sex

1. Oral sex
2. HPV Sexually transmitted
3. HPV
4. Change sexual practice
5. Lifestyle

Health information

1. HPV as cause of HNC
2. Incidence
3. Cervical cancer
4. Screening for HNC
5. Symptoms
6. Case study
7. Treatment
8. Early diagnosis
9. Detection of HNC
10. Normalising HPV
11. Better prognosis
12. Survival rates
13. Demographics
14. Reference to research

HPV vaccination

1. Vaccination
2. Vaccination of boys
3. Vaccine against cervical cancer
4. Ethics around the vaccine
5. Research needed for vaccine effectiveness for HNC

APPENDIX 5.3: STUDY 2 - EXAMPLE NEWSPAPER ARTICLES

Daily Mirror
February 28, 2014 Friday
Edition 1;
Northern Ireland

Sex link to worrying rise of mouth cancer

BYLINE: MIRIAM STOPPARD

SECTION: FEATURES; OPINION, COLUMN; Pg. 38

LENGTH: 402 words

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Why boys should have cervical cancer jab too

BYLINE: LAURA STOTT

SECTION: ME;NEWS; Pg. 6,7

LENGTH: 1080 words

[illegible]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

APPENDIX 6.1: STUDY 3 - PUBLISHED PAPER

ORIGINAL ARTICLE

Discussing a diagnosis of human papillomavirus oropharyngeal cancer with patients: An exploratory qualitative study of health professionals

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ABSTRACT: *Background.* The role of human papillomavirus (HPV) in oropharyngeal squamous cell cancer (SCC) has now been well established. Clinicians' experiences and challenges of talking to patients about HPV have yet to be explored.

Methods. Fifteen health professionals caring for patients with oropharyngeal SCC were interviewed. Interviews were analyzed thematically.

Results. Participants expressed mixed views about explaining the causal role of HPV to their patients. Normalizing HPV and emphasizing the positive prognosis associated with it were regarded as key messages to be communicated. Challenging experiences included managing couples in a consultation and patients' concerns about transmitting HPV to their part-

ners. Some participants described limitations to their HPV knowledge and identified the need for further information and training.

Conclusion. This study identified challenges experienced by health professionals working with patients with oropharyngeal SCC and highlights some key messages to convey to patients. Clinical guidance for health professionals and further information for patients about HPV-positive oropharyngeal SCC are needed. © 2015 The Authors. *Head & Neck* Published by Wiley Periodicals, Inc. *Head Neck* 38: 394–401, 2016

KEY WORDS: human papillomavirus (HPV), oropharyngeal cancer, health professionals, qualitative research, communication

INTRODUCTION

The etiological role of human papillomavirus (HPV) in oropharyngeal squamous cell carcinoma (SCC) has been well established through epidemiological studies.^{1–4} High-risk, sexually transmitted HPV types are thought to be responsible for up to 5% of cancers worldwide, including cervical, anal, penile, vaginal, vulva, and some oropharyngeal cancers.⁵ In the United Kingdom, incidence rates for HPV-positive oropharyngeal SCC have doubled from 1 per 100,000 to 2.3 per 100,000 in just over a decade.⁶ The declining incidence of HPV-negative oropharyngeal SCC, the main risk factors for which are tobacco and alcohol use, means that HPV-positive oropharyngeal SCC now constitutes an increasing proportion of oropharyngeal SCCs overall.⁷ HPV-positive oropharyngeal SCC seems to be biologically and clinically distinct from other head and neck cancers.⁸ Presence of HPV is associated with improved prognosis and there is increasing interest in de-escalating treatment in patients with HPV-positive disease.⁹

In addition to differences in tumor biology and clinical prognosis, the demographic profile of patients with HPV-

positive oropharyngeal SCC differs from those diagnosed with HPV-negative oropharyngeal SCC. Patients with HPV-positive oropharyngeal SCC are more likely to be men, white, under 50 years old, married, educated, and employed^{8,10} compared with their HPV-negative counterparts. This brings with it different treatment and rehabilitation needs, because patients tend otherwise to be in good health, without any traditional risk factors or comorbid disorders.⁸

For these reasons, HPV testing has been introduced as a clinical standard of care in oropharyngeal cancer in the United States, under the National Comprehensive Cancer Network guidelines.¹¹ Testing tumors for HPV is also taking place in some United Kingdom centers, although no specific guidelines have been published. This change in clinical practice, together with the increasing prevalence of HPV-positive oropharyngeal SCC, means that clinicians are beginning to discuss HPV with their patients with head and neck cancer.

A diagnosis of HPV-positive oropharyngeal SCC is not only a cancer diagnosis, with all the associated psychological implications, but also conveys the information that the cancer was caused by a sexually transmitted infection. The sexually transmitted nature of HPV creates a potential challenge for health professionals with little experience of discussing sexual behavior.^{12–14} The possible implications of this shift were neatly summarized in a recent editorial in the *British Dental Journal*: “If talking about tobacco and alcohol habits have seemed like difficult subjects to raise, then talking about oral sex may present a further challenge.”¹⁵ Evidence from the cervical

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cancer literature suggests that general practitioners and practice nurses often lack knowledge of HPV and find the topic sensitive, awkward, and difficult to explain in a way patients can understand.¹⁶ From the patient's perspective, an HPV diagnosis has the potential to cause feelings of stigma and shame in addition to the anxiety and health concerns usually associated with abnormal cervical screening results.¹⁷ In the absence of any formal recommendations for discussing HPV test results with patients with oropharyngeal SCC, a recent review¹⁸ suggested that the cervical cancer literature could be used to provide a starting point.

The experiences of patients with HPV-positive oropharyngeal SCC have begun to be explored; a qualitative study with male HPV-positive oropharyngeal SCC survivors in New York found that some participants were concerned about infecting a partner with HPV and some had discontinued oral sex or deep kissing even with long-term partners. Physicians were the primary source of information for all participants who wanted to know about HPV.¹⁹ In a small study exploring the information needs of patients with HPV-positive oropharyngeal SCC in Texas,²⁰ around half reported that their oncologist did not discuss issues related to HPV with them. Many of these patients sought information about HPV and cancer elsewhere.

It has been argued that health professionals have an ethical obligation to ensure accuracy and transparency when disclosing HPV as the cause of a patient's cancer,²¹ but, as yet, there have been no studies exploring this among health professionals themselves. We therefore carried out an exploratory qualitative interview study with clinicians treating patients with HPV-positive oropharyngeal SCC to explore their experiences and the perceived challenges of talking to patients about HPV in this context. The purpose of the study was to map a broad range of experiences and views from professionals working with this patient group, and seek explanations for differences in experiences, in the hope that this work would inform future quantitative studies.

MATERIAL AND METHODS

Sample

Participants were health professionals caring for patients with HPV-positive oropharyngeal SCC. We used purposive sampling to recruit participants from different disciplines in order to explore a range of perspectives. Participants were recruited via email from 8 research-active hospitals in England and Wales (see Table 1) where HPV is discussed with patients. Potential participants were initially identified through existing contacts (2 surgeons and 2 oncologists) and we subsequently used snowballing. The first author also attended multidisciplinary team meetings at 2 hospitals in London to introduce the study and recruit participants. Initially, we aimed to purposively recruit 10 participants to include oncologists, surgeons, and nurses as they have the most contact with patients with HPV-positive oropharyngeal SCC. As the study progressed, we included some additional professional groups also key to the care of patients with HPV-positive oropharyngeal SCC, to try to maximize the range of views. No new themes emerged from the final 3 inter-

TABLE 1. Sample characteristics.

Characteristic	No. of participants (n = 15)
Age [median (range)]	47 (33–59)
Sex	
Male	8
Female	7
Ethnicity	
White British	13
Other	2
Profession	
Surgeon	5
Clinical oncologist	3
Specialist nurse	4
Research nurse	1
Specialist radiographer	1
Speech and language therapist	1
Geographic area of sample, no.	
North West England	4
North East England	2
South West England	1
London	4
South East England	3
Wales	1

views, suggesting saturation had been achieved. We ceased data collection at this point and therefore no more interviews were conducted.²² Before the interview, each participant completed a short demographic questionnaire and provided written informed consent. The study was approved by the UCL Research Ethics Committee (reference number 4577/001).

Procedure

Semi-structured interviews were carried out in May and June 2013. The interview followed a topic guide that was developed using the existing literature on patient experiences and previous work on HPV and cervical cancer. It covered the participants' professional background and experience of working with patients with head and neck cancer, and their experiences of and attitudes toward communicating with patients about HPV-related head and neck cancer. Suggestions for facilitating communication in the future were also discussed.

Interviews took place face-to-face at the participant's workplace ($n = 7$) or over the telephone ($n = 8$), they lasted 20 to 40 minutes, and were digitally recorded. All interviews were conducted and transcribed verbatim by the first author (R.D.).

Analysis

The interviews were analyzed using Framework Analysis.²³ This approach involves the organization of data into a thematic framework that enables close inspection of the data by theme and by participant.

Rachael Dodd familiarized herself with the interviews by listening to, transcribing, and reading the transcripts, making notes on recurring themes and summarizing each interview. Themes were identified and developed into a thematic framework with subthemes under each main theme. Using the qualitative package NVivo 10, these

data were summarized and organized into a matrix, where each column represented a subtheme and each row represented a participant. Laura Marlow and Jo Waller read half the transcripts each and were involved in developing the thematic framework.²⁴ Any disagreements in interpretation were resolved by discussion.

RESULTS

We interviewed 15 clinicians from a range of professional groups. There was an even mix of male and female health professionals, with most being from white British backgrounds. Clinical oncologists in the United Kingdom administer both chemotherapy and radiation. Characteristics of the sample are shown in Table 1.

Significance of human papillomavirus in oropharyngeal squamous cell carcinoma

All participants regarded the role of HPV in oropharyngeal SCC as an important issue, describing HPV-positive oropharyngeal SCC as a “different disease entirely” (participant 9, female, specialist radiographer), affecting younger, otherwise healthy patients. The rise in incidence was a key concern. Participants reported being able to tell which patients had HPV because of their appearance and demographic background, which differed from the patients they usually treated. As one oncologist reported: “When I first started in head and neck cancer practice, the stereotype of the head and neck cancer patient was pretty well fulfilled in that most of our patients were alcohol dependent, nicotine dependent and had developed head and neck cancer as a consequence of those two risk factors, but we have seen a change ... over the last ... decade where increasingly we’re seeing younger, non-smoking, non-drinking patients who are on average 10 years younger and recognizing in that patient group that their HPV associated disease is the main risk factor for that” (participant 3, male, clinical oncologist).

The clinical implications of HPV-positive oropharyngeal SCC were discussed, including patients living longer with the after-effects of treatment and patient demands for expedited rehabilitation. One participant explained the impact of this: “we’ve got a longer period of survivorship for younger people who are still actively employed and so their functional rehabilitation becomes a bigger issue so that’s going to be a bigger part of our case load” (participant 12, female, speech and language therapist).

Attitudes to discussing human papillomavirus

Almost all participants had talked about HPV with their patients, but even those who did not have direct experience of this were able to express their opinions on the issue. Views about disclosing HPV as the cause of a patient’s cancer varied, perhaps reflecting the lack of guidelines for discussing HPV. There was a range of views on the possible benefits of discussing HPV status with patients.

Participants who felt it important to discuss HPV status believed it was “helpful for the patients’ psyche” (participant 4, male, surgeon) to understand the cause of their cancer. Sometimes patients had done their own research about HPV and had become “scared about it” (participant

10, female, clinical oncologist), making it important to provide them with accurate and reassuring information. A clinical oncologist described how patients would search for information about HPV on the internet, and felt that avoiding the issue in the clinic was unhelpful.

In centers running clinical trials, it was viewed as difficult not to mention HPV, because HPV status determined eligibility that “forces the issue” (participant 2, male, surgeon). One reason for discussing HPV was the positive prognosis of HPV-oropharyngeal SCC, which participants felt had a direct impact on the patient and was seen as “one of the major bits of information they want to know” (participant 6, male, surgeon).

Participants who did not discuss HPV status with patients felt it unnecessary to mention HPV because it is “not offering a modifiable risk factor” (participant 3, male, clinical oncologist) and focusing on the cause may contribute to self-blame for past behavior: “When it comes to HPV disease, I mean what can you tell them? ... there’s nothing that they need to adapt in their lifestyle which is going to make any difference to their outcome at all” (participant 7, male, surgeon).

One view was that patients were not concerned about the cause of their cancer during the diagnosis consultation, where other worries and discussions about treatment took priority: “not a single patient that I’ve met so far has asked me what’s caused their cancer” (participant 7, male, surgeon). It was sometimes felt to be best to “leave it at that stage, to the patient and their family [to raise]” (participant 1, male, surgeon) because of the fact that it does not change the clinical management. The consultation was sometimes described as being patient-directed and if patients did not ask about it, HPV “may just not come up” (participant 3, male, clinical oncologist). Some participants said they were increasingly raising the issue of HPV with their patients, whereas others described patient-led consultations. Mentioning clinical trials prompted patients to ask questions, but 1 surgeon reported “less than 10% of patients coming back at a later stage to discuss the implications [of HPV] in a social context” (participant 1, male, surgeon).

Variations in attitudes toward communicating about HPV among health professionals were described, including a difference between surgeons and clinical oncologists: “I would say the oncologists talk about it much more easily and freely and openly, whereas the surgeons might mention it, but they don’t go into how it’s caused, the whole thing about HPV. No, I’d say oncologists are better at communicating about it” (participant 8, female, specialist nurse).

Challenges to discussing human papillomavirus

Health professionals described 2 main concerns when talking to patients about HPV: the limitations of their own knowledge about the virus and discomfort talking about sexual health matters.

Knowledge. It was apparent that some of the health professionals felt they lacked knowledge to respond to some of the questions patients asked about HPV, with a specialist nurse reporting “no bottom to those questions” (participant 11, female, specialist nurse). It appeared there was

some uncertainty about where to find accurate information, with consultants sometimes reported as giving different information to that printed in journals: "he [consultant] said 'Oh it's not an epidemic' ... am I supposed to go with what he says, or am I supposed to go with what's in the journals?" (participant 11, female, specialist nurse). The issue was raised of not feeling well-informed, while it was suggested that some questions are difficult to answer because of the limits of scientific knowledge: "they start asking questions about how I caught HPV and when I caught it and who I caught it from, how will I have caught it. And some of those questions are difficult to answer because we don't have the scientific knowledge at the moment ... it's still quite confusing I think both for the doctors and for the patients" (participant 5, male, clinical oncologist).

Being honest with patients about not knowing the answers was advocated, because there is still scientific uncertainty: "one of the questions I have been asked is 'So now the cancer's gone, if I have oral sex again, is it going to come back?' I don't know that answer, I don't know if anybody does know that answer ... if the questions are difficult like that, I tend to say there's a lot of research on the go at the moment and we don't have all the answers to the questions" (participant 13, female, research nurse).

There was some evidence of discomfort talking about HPV with patients. A specialist nurse said: "I'd feel out of my depth pretty quickly if people had been on the internet and they'd heard this and heard that" (participant 11, female, specialist nurse). However, confidence seemed to increase with experience, with an oncologist describing how she felt she could now honestly say "nobody knows the answer" (participant 10, female, clinical oncologist).

Talking about sexual health. Health professionals working with patients with head and neck cancer are not used to discussing sexual health and some participants were very aware of this: "You end up getting into the field of how was the virus transmitted and you say well it'll be broadly speaking through sexual contact and actually it's uncommon for patients to want that spelled out, but just occasionally I've got into a conversation between like as it were vaginal sex, oral sex, kissing and all of that. People want it spelled out in words of one syllable, but I think to be honest most head and neck consultants get pretty squeamish about that" (participant 2, male, surgeon).

Observations were raised about participants' colleagues: "I'm very lucky to work with some extremely talented surgeons, ... but I think talking about HPV takes them out of their comfort zones somewhat ... they are empathetic enough communicators to know what they're not good at and I think they'd know that they're straying out of their comfort zone; better not to get into it" (participant 3, male, clinical oncologist).

In addition, the issue of potential blame or "finger pointing" (participant 6, male, surgeon) in relation to sexual transmission was raised. One participant observed that "it can be particularly difficult when you have couples in a session" (participant 12, female, speech and language therapist). There were also concerns about not wanting to give the information in the "wrong manner" and worry about patients leaving the consultation blaming themselves. Not

all participants reported difficulties talking about sexual matters, with the speech and language therapist being experienced in, for example, dealing with "difficult questions about ... engaging in sexual practice when I have a stoma" (participant 12, female, speech and language therapist).

Dealing with the impact of human papillomavirus on relationships

It was suggested that consultations could be influenced by the presence of the patients' partners and that some patients were more open to discussion about HPV without their partners present. For example, one couple had researched HPV before the consultation and the partner was concerned about whether HPV indicated infidelity: "Both husband and wife had done their homework, they knew about HPV, they knew he was likely to be HPV positive before the consultation started ... but the main crux of this issue was that ... the wife was [saying] 'How's he got it, when did he get it.' As far as the wife was concerned they'd been in a monogamous relationship for 15 years and she felt ... this must be a sign that he'd been unfaithful and had other partners outside of the marriage ... that was obviously causing some problems between the two of them" (participant 5, male, clinical oncologist).

The techniques described below (see Key messages) for normalizing HPV and emphasizing its high prevalence were used to try and diffuse the issues around past and/or present sexual activity. Clinicians often tried to help patients realize it was not their fault and that there was nothing they could have done to prevent their cancer.

Fear of transmission and self-blame among partners were also described. In 1 case, a consultation had resulted in the couple ceasing sexual activity, which had led the clinical oncologist to re-assess how issues of sexual transmission should be communicated: "we've been on a real learning curve with that [discussing HPV] and I know I got it wrong initially ... we talked about it with a patient and in subsequent discussions with the support workers, that patient was not having sex with his wife anymore because he was worried he would infect her with HPV" (participant 3, male, clinical oncologist).

A surgeon also recognized the nature of the relationship as important when deciding how much to discuss in the consultation: "I was just slightly cautious ... about discussing with partners the number of partners someone else has had ... because obviously it was a newer relationship, not a sort of you know, 20 years married type one" (participant 6, male, surgeon).

The same surgeon (participant 6, male, surgeon) described the difficulty of talking to couples when each individual had different questions and concerns. In 1 case, the patient was more focused on the details of the treatment, but his wife was more concerned about outcome and survival. This demonstrates the different approach health professionals may have to take in joint consultations.

Patient concerns and questions about human papillomavirus

Almost all participants gave examples of concerns and questions patients had expressed about HPV. Views

differed among health professionals about what patients' primary concerns were. Some participants reported concerns mainly about diagnosis and treatment; with others reporting concerns and questions about HPV and transmission (see previous section). One specialist nurse reported an experience with a patient worried about transmitting HPV to his wife and re-infecting himself if he continued to practice oral sex. This patient was also worried about his son and talked about getting him vaccinated: "I had this one guy who was HPV positive and obviously he was really worried about passing this onto his wife or being re-infected by HPV if he continued to practice oral sex... He also was really worried about his son... because he knew that girls are being vaccinated against the HPV virus. He was worried that his genetic makeup, that he's developed a cancer by the HPV virus, that his son was going to and he was looking into getting his son vaccinated privately" (participant 15, female, specialist nurse).

Specialist nurses described how some patients "come armed with" (participant 8, female, specialist nurse) lots of questions about implications for transmission and the chances of becoming re-infected, but also noted that others "probably wouldn't ask many questions" (participant 11, female, specialist nurse). Some nurses thought that patients felt more comfortable asking them questions than the surgeon or clinical oncologist. This was acknowledged by some surgeons who said that it was the specialist nurses who were asked follow-up questions. Nurses and allied health professionals tended to see it as their role to be "the patients' advocate" (participant 8, female, specialist nurse), checking whether they had any questions after the consultation.

Key messages

Several key messages about HPV were highlighted by participants, suggesting an agreement about core messages perceived to be useful to the patient. These focused on trying to minimize possible negative psychological responses to HPV and presenting the diagnosis in a way that was easy to understand and emphasized its positive implications. Recognizing the amount of information each patient could understand and tailoring communication to avoid overloading them was mentioned by participants as important. It was suggested that delivering information about HPV in a factual manner "can distance any emotive element" (participant 12, female, speech and language therapist), with the aim of "not making a big deal of it" (participant 10, female, clinical oncologist).

Normalizing human papillomavirus. Participants reported a range of ways they would try to normalize HPV infection and reduce its psychological impact. This included describing the high prevalence of HPV, highlighting that transmission is through normal sexual behavior, and using the context of cervical cancer and HPV vaccination.

High prevalence. HPV was often normalized by explaining that anyone who is sexually active will have been exposed to it: "it's just really a difference between how the body deals with it in different people" (participant 4,

male, surgeon). The importance of communicating the fact that HPV is "a ubiquitous problem" (participant 5, male, clinical oncologist) was emphasized; a surgeon reported telling his patients that HPV is as common as flu, calling it "genital flu" (participant 6, male, surgeon).

Normal sexual behavior. Participants emphasized that HPV was caused by normal sexual behavior and was not an indication that the patient was promiscuous: "this is something which is associated with probably any sexual relationship... it's not like getting a dose of gonorrhea or chlamydia" (participant 4, male, surgeon). It was suggested that by being deliberately vague about the nature of transmission, it was possible to reassure the patient that almost anything could have caused it: "I say you can get it from kissing somebody... that may not be the most common way to get it but you could" (participant 5, male, clinical oncologist). Participants also emphasized the fact that HPV is an infection likely to have occurred a long time ago and that the patient had "not gone out and slept with an infected individual" (participant 4, male, surgeon).

Link with cervical cancer/human papillomavirus vaccination. Referring to HPV in the context of cervical cancer was reported to help patients understand that the same virus is involved in both cancers. Mentioning the HPV vaccination program was thought to convey to the patient that this virus "isn't something special" (participant 3, male, clinical oncologist) and 1 surgeon described how he would explain this: "I always explain that it's the same virus that's related to cervical cancer and that anyone that's sexual active will have been exposed to it, hence the vaccination program for pre-sexually active individuals" (participant 4, male, surgeon).

No need to change behavior. When patients were concerned that they had "caused" their cancer, participants reassured them that there was no need to modify their behavior. Participants explained how they would tell patients with cancer related to tobacco and alcohol use to change their behavior as this was important for their prognosis, whereas for patients with HPV-positive oropharyngeal SCC "there's no change in their behavior related to the sexual practice right now that you're advising them to take" (participant 2, male, surgeon), as this would not affect the outcome.

Positive prognosis. Participants tried to convey the positive prognosis of HPV-positive oropharyngeal SCC, with 1 clinical oncologist reporting how this information is useful: "I think where knowledge of HPV status is useful to the patient, is enabling them to understand yes you've got head and neck cancer but we know that this particular head and neck cancer carries a much better prognosis than other forms of head and neck cancer" (participant 3, male, clinical oncologist).

Conveying the message about prognosis was viewed by most of the health professionals to help counter any feelings of blame and guilt among patients seeing this as "a bit of good news for them" (participant 7, male, surgeon).

and was sometimes accompanied by a comparison to head and neck cancer related to smoking and other risk factors, using terms such as doing “better in the long term” (participant 4, male, surgeon) and a “better prognosis” (participant 6, male, surgeon).

Professional development

Learning from experience. As health professionals saw an increasing number of HPV-positive oropharyngeal SCC cases, they felt they had begun to learn what is relevant for patients. One clinical oncologist described how in the past he had “mentioned unnecessarily orogenital transmission and that’s not actually relevant” (participant 3, male, clinical oncologist).

A transition was evident, from participants previously talking about contracting HPV through oral sexual behaviors, to now talking about most sexually active people contracting HPV. In some cases, participants reported having identified areas of discussion they avoided because of their lack of knowledge. They had since made an effort to find out more, resulting in increased confidence and more open discussions about HPV. Knowing the latest research and reading the literature was of upmost importance: “I mean for us it was finding out more information and having the knowledge to answer questions ... then also just learning from experience about the types of things that people are asking, ... doing your best to find out what the answer to that question is for the next person to ask. Because if one’s [patient] going to ask, the next are” (participant 15, female, specialist nurse).

Learning from others. Regular team updates and feedback with colleagues were mentioned as useful to improve dissemination of information to the patient in the future. It was acknowledged that colleagues “think differently” (participant 1, male, surgeon) so working as a multidisciplinary team was viewed as very important. Attending conferences was also perceived as a valuable way to both increase knowledge about the area and learn alternative ways to discuss HPV-positive oropharyngeal SCC.

There was agreement over the need to add to and provide consistent information to patients with HPV-positive oropharyngeal SCC: “incorporating it in our ... patient information ... I certainly think that there will be serious room for improvement in that” (participant 14, male, specialist nurse).

It was also suggested that a leaflet and/or guidelines offering advice for health professionals would be useful. Another suggestion was learning from colleagues working in cervical cancer, as they have “done a very good job in that women with cervix cancer don’t get immediately vilified for being sexually promiscuous and that’s not the public conception of cervix cancer” (participant 5, male, clinical oncologist).

Training. Communication workshops and training were mentioned as a way of developing further skills: “we would be best off receiving some degree of training in terms of how to communicate this information to patients” (participant 7, male, surgeon). In some centers, communication workshops had already been carried out

and participants from these centers felt they had benefited.

DISCUSSION

This is the first study to explore the views and experiences of health professionals talking to patients about HPV in the context of oropharyngeal SCC. Views about discussing patients’ HPV status were mixed. Some felt it was beneficial for the patient to know the cause of their cancer, others felt that as clinical management is not currently determined by HPV status, discussing HPV in consultations was not necessary. Most health professionals in this sample did talk to their patients about HPV, with discussions sometimes initiated by the health professional and sometimes by the patient.

Participants described several key messages about HPV that they felt were important to incorporate into their discussions with patients. Describing the high prevalence of HPV and its link with normal sexual behavior, and explaining HPV using the context of cervical cancer and HPV vaccination helped to normalize the infection. Discussion of oral sex specifically was deemed unhelpful, and recent United Kingdom evidence confirms that oral sex is commonplace, with the majority of people reporting oral sexual contact in the last year, and numbers rising in younger age groups.²⁵ In the cervical cancer literature, the high prevalence of HPV has been an important message to convey to patients and has been shown to reduce stigma and embarrassment.^{17,26} Previous literature has suggested because of a lack of research regarding the psychosocial impact of HPV on patients with oropharyngeal SCC, that it is helpful to look to the counseling messages used in the cervical cancer literature,^{18,27} although the psychosocial implications for patients with HPV-positive oropharyngeal SCC may be different. Our participants also felt it was important to explain that HPV-positive oropharyngeal SCC tends to have a positive prognosis. Qualitative work with patients with HPV-positive oropharyngeal SCC suggests that they are encouraged by this information,¹⁹ supporting this as a key message for health professionals to convey. A potential implication of explaining the good survival rates to patients with HPV-positive oropharyngeal SCC is a resulting preference for de-escalation of treatment, as 1 surgeon described. Ongoing clinical trials⁹ are exploring the possibility of de-escalating treatment for HPV-oropharyngeal SCC, and once the results of these trials are published clinical guidelines should be available. Until then, health professionals may still need to be prepared for conversations about de-escalating treatment, especially with highly informed patients.

Qualitative work with patients with HPV-positive oropharyngeal SCC suggests that questions about HPV are overshadowed by concerns about cancer.¹⁹ Some of the nurses that we interviewed described a lack of confidence answering questions about HPV largely because of their own lack of knowledge. Given that nurses are often the first point of contact for patients with questions, it is important that information and training is available to increase their knowledge and improve their confidence for these discussions. Surgeons and clinical oncologists also felt there was a general lack of knowledge about

HPV and oropharyngeal SCC, but understood this was due to limited scientific knowledge and were generally confident explaining this to patients. Most of the health professionals we interviewed felt that additional training could help them improve their knowledge about HPV and communication with their patients with HPV-positive oropharyngeal SCC, supporting previous research with dentists and dental hygienists.¹² Some of the participants we interviewed felt that communicating with patients with HPV-positive head and neck cancer was very different from communicating with patients whose cancer was related to tobacco and alcohol use. Patients with HPV-positive oropharyngeal SCC would usually be given more information about the cause of their cancer and this often brought with it the need to discuss sexual behavior. These discussions have the potential to cause problems in relationships, demonstrated by some of the cases described in this study and previous findings from Baxi et al.¹⁹ This should therefore be something health professionals consider when planning treatment and recommending support for patients.

The findings from this study mirror those of similar studies in the cervical cancer literature.¹⁶ This suggests significant overlap in the concerns of health professionals from the 2 fields. Research into common questions asked by patients^{28,29} and educational needs of health professionals from the cervical cancer literature³⁰ could therefore be useful to head and neck cancer clinicians. It is important to consider, however, that the needs and concerns of patients with HPV-positive oropharyngeal SCC are likely to differ from those of patients with cervical cancer because, in part, to that fact that a high proportion of patients with HPV-positive oropharyngeal SCC are men.^{6,31}

We sampled a range of health professionals across England and Wales to gain perspectives on communicating about HPV-positive oropharyngeal SCC from different disciplines. This work offers a useful starting point, which could contribute to the development of information for health professionals and potentially inform larger quantitative work with patients with HPV-positive oropharyngeal SCC, with the ultimate goal of developing information for patients. Conducting this study using qualitative methods enabled the complexities of the consultation to be discussed; however, we acknowledge a number of limitations to the study. The health professionals in this study may have been those who are more comfortable talking about HPV, so it is possible that additional themes may have arisen in those who do not talk about HPV, as these were difficult to sample. Participants may also have personal biases, which could influence the discussion of sensitive topics, such as sexually transmitted infections. We were not able to draw comparisons between the different professional groups because of small numbers, but this could be an important avenue of future research. Patients' views were not explored in this study, so caution is also needed when interpreting the data about patients' concerns, as these are all from the perspective of the health professionals.

The demographic characteristics of patients with HPV-positive oropharyngeal SCC present new challenges for health professionals in terms of the questions being asked, the factors important to the patients, and their rehabilitation and treatment needs. Experiences among health pro-

fessionals differed, suggesting a need for clinical guidance for communication about HPV in this context to ensure that patients are receiving consistent messages. Further research is needed with patients to explore what being diagnosed with HPV-positive oropharyngeal SCC means for them. There is a wealth of information available in the cervical cancer literature that could be usefully adapted for health professionals caring for patients with HPV-positive oropharyngeal SCC.

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APPENDIX 6.2: STUDY 3 – UCL ETHICS APPROVAL

UCL RESEARCH ETHICS COMMITTEE
GRADUATE SCHOOL OFFICE



Dr Jo Waller
HBRC
Department of Epidemiology and Public Health
1-19 Torrington Place
UCL

5 March 2013

Dear Dr Waller

Notification of Ethical Approval

Project ID: 4577/001: Understanding how clinicians communicate with patients about HPV as a cause of head and neck cancer

I am pleased to confirm that in my capacity as Chair of the UCL Research Ethics Committee I have approved your study for the duration of the project i.e. until March 2014.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events

For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research.

Yours sincerely



Professor John Foreman
Chair of the UCL Research Ethics Committee

Cc:
Rachael Dodd, Applicant
Professor Richard Watt, Head of Department

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APPENDIX 6.3: STUDY 3 - INFORMATION SHEET

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix C (Version 1, 21/02/13)

Participant Information Sheet

Title of project: Understanding how clinicians communicate with patients about HPV as a cause of head and neck cancer

We would like to invite you to participate in a research study about your experiences of communicating with and treating patients with human papillomavirus (HPV)-related head and neck cancer (HNC). Your participation is completely voluntary. Before you decide if you want to take part in this research, please read the following information carefully. Ask us if there is anything that is unclear or if you would like more information.

Who are the researchers?

We are a group of researchers from the Health Behaviour Research Centre at University College London. Our research is aimed at understanding health behaviour related to cancer screening, smoking, and dietary choice. Through previous research we have worked with a range of different groups from the population, some of which has included clinicians and other health professionals.

Why is this study taking place?

HPV is one of the most common sexually transmitted infections in the UK and has been implicated in the development of some head and neck cancers. As you may know, the incidence rate of HPV-related HNCs has been increasing. We want to find out about the experiences of clinicians and health professionals who communicate with and treat patients with HPV-related HNC. The study will help to develop ways of facilitating communication between clinicians and patients on this topic in the future.

What will I need to do?

If you agree to participate in this research project you will be interviewed by a member of the research team which will take approximately 30 minutes. The interview will ask about your experiences of discussing cancer causes with patients, in particular those diagnosed with HPV-related HNC. We would also like to discuss ways in which future communication of this topic could be facilitated. This interview can either be carried out face-to-face at a convenient location for you, or as a telephone interview. The interview will be recorded and transcribed verbatim. The transcript will be anonymised so that any details that could identify you will be removed.

Do I have to take part?

Your participation is completely voluntary. If you decide to participate you may keep this information sheet with the researcher's contact information if you have any questions. You are free to withdraw at any time without giving a reason.

Will my responses be anonymous?

Yes. It will not be possible to match any information you give us during the interview to your name. Our procedures for storage, processing, handling, and destroying the information you give us are in line with the Data Protection Act (1998). All information will be anonymous and will be kept securely for 20 years. After 20 years all information will be securely destroyed.

Project ID: 4577/001
Version 1 (21/02/2013)

What are the benefits and disadvantages of participating?

By participating you will be contributing to important research that helps us understand more about how health professionals communicate with patients diagnosed with HPV-related HNC.

What if I don't want to be part of the study anymore?

If you decide that you do not wish to be part of the study after a date for the interview has been arranged, contact the research team and they can cancel your appointment and withdraw you from the study. If you decide after the interview has taken place that you wish to withdraw from the study you can contact us and all the information you have given us will be destroyed.

What will happen to the results?

We will publish the findings in academic journals and present them at conferences to other people interested in cancer prevention and communication. You can request a copy of the final report if you would like to see the results of the study.

What if I have further questions?

An independent group called the University College London Research Ethics Committee has approved this study. If you have a concern about any aspect of this study, please contact the researchers who will do their best to answer your questions.

Thank you for taking time to read this, we hope you decide to participate in the study.

Dr Jo Waller and Rachael Dodd

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For more information about the Health Behaviour Research Centre: <http://www.ucl.ac.uk/hbrc>

APPENDIX 6.4: STUDY 3 - DEMOGRAPHIC QUESTIONNAIRE

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix B (Version 2, 09/05/13)

Participant Demographic Questionnaire

We would just like to ask some questions about you and your professional background:

1. What is your age?
2. Are you: Male ☐ Female ☐
3. Which of these best describes your ethnic group?

White British	<input type="checkbox"/>
White Irish	<input type="checkbox"/>
Other White background	<input type="checkbox"/>
Caribbean	<input type="checkbox"/>
African	<input type="checkbox"/>
Other Black background	<input type="checkbox"/>
Indian	<input type="checkbox"/>
Pakistani	<input type="checkbox"/>
Bangladeshi	<input type="checkbox"/>
Other Asian	<input type="checkbox"/>
White and Asian	<input type="checkbox"/>
White and Black Caribbean	<input type="checkbox"/>
White and Black African	<input type="checkbox"/>
Other Mixed	<input type="checkbox"/>
Chinese	<input type="checkbox"/>
Any other	<input type="text"/>

Project ID: 4577/001
Version 2 (09/05/2013)

4. What is your highest level of qualifications?

5. What is your profession?

Surgeon ☐

Oncologist ☐

Specialist Nurse ☐

Other, please specify:

6. How many years have you been practicing in this profession as:

a. A trainee

b. Qualified

7. Where do you work?

Hospital ☐

Hospice ☐

Rehabilitation Centre ☐

Other, please specify:

8. On average, how many cases of HPV positive head and neck cancer are seen in your centre per year?

9. Approximately how many of these cases are you involved in?

APPENDIX 6.5: STUDY 3 - CONSENT FORM

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix D (Version 1 21/02/2013)

Consent Form

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: Understanding how clinicians communicate with patients about HPV as a cause of head and neck cancer

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 4577/001

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

Participant's Statement

I

- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- understand that my participation will be taped/video recorded and I consent to use of this material as part of the project.
- consent to the processing of my personal information for the purposes of this research study.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signed:

Date:

APPENDIX 6.6: STUDY 3 - PARTICIPANT DEBRIEF

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix E (Version 1, 21/02/13)

Participant Debrief

Thank you very much for taking the time to talk to me today. Everything we have talked about today will remain confidential and your responses will be anonymous. Only the research team will have access to your interview transcript.

You have taken part in this research to help us explore and understand the how clinicians communicate with patients with a diagnosis of HPV-related head and neck cancer. We are hoping your responses will be used to develop materials to facilitate communication about the HPV and HNC in the future.

If you have any further questions or concerns about the study after today, please feel free to contact a member of the research team.

Dr Jo Waller and Rachael Dodd

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For more information about the Health Behaviour Research Centre: <http://www.ucl.ac.uk/hbrc>

APPENDIX 6.7: STUDY 3 - INTERVIEW TOPIC GUIDE

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix A (Version 1, 21/02/13)

Interview Topic guide

Clinicians (e.g. head and neck)

Introduction
<ul style="list-style-type: none"> o Background and aims of the study o Confidentiality o Timing and tape recording o Use of data (reports; papers; data sharing)
Background
<ul style="list-style-type: none"> o Professional background (oncologist, nurse etc.) o Experience of working with HNC patients (how long for, in what capacity?)
Communication with patients
<ul style="list-style-type: none"> o Experience of discussing cancer causes with patients o Is HPV talked about? o Difficulties / anxieties o Patient responses (confusion, stigma/shame, questions) o If not discussed, why not? o Experience of other colleagues (is the issue discussed with colleagues) o Is this seen as an important issue in the field? o How is talking about HPV similar to or different from talking about other causal factors (e.g. drinking alcohol and smoking). Explore issues around sexual transmission if not raised before.
Facilitating communication (if difficulties are identified)
<ul style="list-style-type: none"> o Is there anything that would make communication easier? o Recommendations for other clinicians from your experience; things that have helped or not been helpful o Need for print materials that would support messages? o Other comments, issues, suggestions
Closing the interview
<ul style="list-style-type: none"> o Thanks o Reassure about anonymity o Give debrief o Ask if we can re-contact later in the study to get feedback on information materials

APPENDIX 7.1: STUDY 4 - ETHICS APPROVAL

**UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES**



12 October 2015

Dr Jo Waller
Health Behaviour Research Centre
Department of Epidemiology and Public Health
UCL

Dear Dr Waller

Notification of Ethical Approval

Project ID: 4577/003: Discussing HPV and head and neck cancer: a survey of health professionals

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee that I have approved your study for the duration of the project i.e. until October 2016.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form': <http://ethics.grad.ucl.ac.uk/responsibilities.php>
2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator (ethics@ucl.ac.uk) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

On completion of the research you must submit a very brief report of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research.

Yours sincerely

**Professor John Foreman
Chair of the UCL Research Ethics Committee**

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<http://ethics.grad.ucl.ac.uk/>

APPENDIX 7.2: STUDY 4 – EMAIL TO POTENTIAL PARTICIPANTS

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix B (Version 1, 19/08/15)

Email to potential participants

I am a doctoral researcher from the Cancer Research UK Health Behaviour Research Centre at University College London. I would like to invite you to complete a short survey about discussing HPV with head and neck cancer patients. I am interested in hearing from health professionals who have and those who have not discussed HPV with their patients in the past. The work will contribute to my research on the psychosocial implications of HPV in head and neck cancer.

We will not ask for any personal details and your responses will be completely anonymous. To find out further information and to take part, please click on the following link:

<https://opinio.ucl.ac.uk/s?s=38577>

If you have any further questions, please do not hesitate to contact me.

Thank you in advance for your help with my research.

Yours sincerely

Rachael Dodd
MRC PhD Student
r.dodd@ucl.ac.uk
020 7679 8254

APPENDIX 7.3: STUDY 4 – PARTICIPANT INFORMATION SHEET

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix C (Version 2, 12/10/2015)

Participant Information Sheet

Title of project: Discussing HPV and head and neck cancer: a survey of health professionals

We are a group of researchers from the Health Behaviour Research Centre at University College London. We would like to invite you to participate in a research study about your experiences of discussing human papillomavirus (HPV)-related head and neck cancer (HNC) with your patients.

What will I need to do?

You will be asked to complete a survey which will take no longer than 10 minutes. By participating you will help us understand more about how health professionals communicate with patients diagnosed with HPV-related HNC.

The survey is completely anonymous and cannot be linked back to you. If you begin the survey you are still free to withdraw at any time without giving a reason and your responses will not be used. It will not be possible to withdraw your responses once the survey has been finished as participation is anonymous.

What will happen to the results?

We may publish the findings in academic journals and present them at conferences to other people interested in cancer prevention and communication. Our procedures adhere to the Data Protection Act (1998).

By completing this survey you consent to having your data included. You are also indicating that you have read and understood the above information and that you are over 18 years of age.

This study has been approved by an independent group called the University College London Research Ethics Committee (Study ID: 4577/003). If you have any further questions about the study please contact Rachael Dodd, r.dodd@ucl.ac.uk or 020 7679 8254.

APPENDIX 7.4: STUDY 4 – PARTICIPANT DEBRIEF

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix D (Version 1, 19/08/2015)

Participant Debrief

Thank you very much for taking the time to complete this survey today. Your responses will remain anonymous and only the research team will have access to your data.

You have taken part in this research to help us understand how health professionals communicate with patients with a diagnosis of HPV-related head and neck cancer. Your responses may be used to develop materials to facilitate communication about HPV and HNC in the future.

If you have any further questions or concerns about the study after today, please feel free to contact the research team.

Rachael Dodd

Health Behaviour Research Centre
Department of Epidemiology and Public Health
University College London
Gower Street
London WC1E 6BT

Telephone: 020 7674 8254

Email: r.dodd@ucl.ac.uk

For more information about HPV and head and neck cancer:

<http://www.throatcancerfoundation.org/hpv>

<http://www.mouthcancer.org/risk-factors/>

APPENDIX 7.5: STUDY 4 – HEALTH PROFESSIONAL SURVEY

Appendix A (Version 1, 19/08/15) Health professional survey

Have you ever heard of HPV?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
Have you ever looked for any information on human papillomavirus (HPV) and head and neck cancer?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't remember <input type="checkbox"/>
If yes, where have you looked?	Other colleagues <input type="checkbox"/>	Internet <input type="checkbox"/>	Medical Journals <input type="checkbox"/>
	Media <input type="checkbox"/>	Conferences <input type="checkbox"/>	Professional organisations <input type="checkbox"/>
	Other <input type="checkbox"/>		

KNOWLEDGE ABOUT HUMAN PAPILLOMAVIRUS (HPV)			
Please read each of the statements about HPV and indicate whether they are true or false by ticking the appropriate box. If you do not know the answer, please tick "Don't know".			
	True	False	Don't Know
HPV often has no visible signs or symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is very rare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A person could have HPV for many years without knowing it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having many sexual partners increases the risk of getting HPV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV can cause cervical cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV usually goes away without needing any treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Most sexually active people will get HPV at some point in their lives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV can cause oral cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The oral tongue is the principal head and neck cancer site associated with HPV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is a relatively uncommon sexually transmitted infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is associated with a much improved prognosis for patients with head and neck cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Most patients with oral HPV experience symptoms of the infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

DISCUSSING HPV WITH PATIENTS					
We'd like to find out your experiences of informing your head and neck cancer patients about HPV.					
Thinking about the patients you treat with HPV-related head and neck cancer, how many of them have you told that their cancer was caused by HPV?	All <input type="checkbox"/>	Most <input type="checkbox"/>	Some <input type="checkbox"/>	None <input type="checkbox"/>	
If you have informed a patient about their HPV status, have you discussed HPV in detail with a patient?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not sure <input type="checkbox"/>	N/A <input type="checkbox"/>	
Generally, how willing are you to discuss HPV with your patients in the future?	Not at all willing <input type="checkbox"/>	Not very willing <input type="checkbox"/>	Neither willing or unwilling <input type="checkbox"/>	Somewhat willing <input type="checkbox"/>	Very willing <input type="checkbox"/>
If you discuss HPV during consultations, who usually initiates the discussion?	Myself <input type="checkbox"/>	Patient <input type="checkbox"/>	Sometimes me; sometimes the patient <input type="checkbox"/>	Other <input type="checkbox"/>	N/A <input type="checkbox"/>

We'd like to know what you think about discussing HPV with their patients.					
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Discussing HPV with patients is important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is helpful for the patient to understand the cause of their head and neck cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is important to provide accurate information about HPV to the patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about HPV is reassuring to patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is important to convey the positive prognosis of HPV-related head and neck cancer to patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is not necessary to tell patients that they have HPV because there's no implications for behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My patients are not concerned about the cause of their cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is not necessary to tell patients whether they have HPV because it doesn't change their clinical management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We'd like to know about how you would feel discussing HPV with a patient.					
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I am confident about initiating a discussion about HPV with a patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can explain HPV in a way that patients can understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can reassure patients that HPV is a result of normal sexual behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can deal with patients' questions and concerns when I talk to them about HPV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking about HPV with a patient is not easy because it's about their sexual behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking to a patient about HPV is embarrassing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am not used to talking about sexual health with my patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes patients' partners are present during consultations. We'd like to know how you would feel discussing HPV with a partner present.					
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
When discussing HPV with a patient and their partner...					
I would use a different approach than if the patient was alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would feel confident discussing the transmission of HPV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would feel comfortable talking about infidelity if this was raised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would feel comfortable talking about their sexual relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

We'd like to know about your attitudes to discussing HPV-related head and neck cancer.					
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I don't have enough information on HPV-related head and neck cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It's hard to keep up-to-date	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I might not have all the answers to patients' questions about HPV-related head and neck cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't want to pass judgement on patients' sexual behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't have enough time to discuss HPV-related head and neck cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't think patients want to know about HPV-related head and neck cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In my view, I don't see any reason to discuss HPV with patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having good leaflets to pass onto them and use during the discussion would help with discussing HPV with patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a clear plan of what I was going to say would help with discussing HPV with patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To keep up-to-date with the latest information about HPV, it would be helpful to:					
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Have regular team updates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have regular feedback of experiences with patients from colleagues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attend conferences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attend further training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

BACKGROUND QUESTIONS	
We would just like to start by asking you some questions about you.	
What is your age?	<input type="text"/>
Are you:	<div>Male <input type="checkbox"/></div> <div>Female <input type="checkbox"/></div>
Did you train in the UK?	<div>Yes <input type="checkbox"/></div> <div>No <input type="checkbox"/></div>
If no, where did you train?	<input type="text"/>
What is your profession?	<div>Surgeon <input type="checkbox"/></div> <div>Oncologist <input type="checkbox"/></div> <div>Specialist Nurse <input type="checkbox"/></div> <div>Other, please specify: <input type="text"/></div>
How many years have you been practicing in this profession?	<input type="text"/>
Where is your main place of work?	<div>Hospital <input type="checkbox"/></div> <div>Hospice <input type="checkbox"/></div> <div>Rehabilitation Centre <input type="checkbox"/></div> <div>Other, please specify: <input type="text"/></div>

APPENDIX 7.6: STUDY 4 – STRONGLY AGREE/AGREE RESPONSES (N/%) TO ATTITUDES AND BELIEFS ABOUT DISCUSSING HPV WITH OSCC PATIENTS

413

	Surgeons (n=96)	Oncologists (n=28)	Specialist nurses (n=40)	Speech and language therapists (n=59)	Other (n=37)	χ^2 (p value)
Discussing HPV with patients is important	83 (86.5)	25 (89.3)	38 (95.0)	55 (93.2)	31 (83.8)	4.27 (0.37)
It is helpful for the patient to understand the cause of their head and neck cancer	86 (89.6)	22 (78.6)	39 (97.5)	55 (93.2)	30 (83.3)	8.66 (0.07)
It is important to provide accurate information about HPV to the patient	87 (90.6)	26 (92.9)	40 (100)	58 (98.3)	37 (100)	10.22 (0.037)
Information about HPV is reassuring to patients	47 (49.0)	14 (50.0)	27 (67.5)	34 (57.6)	17 (45.9)	5.34 (0.254)
It is important to convey the positive prognosis of HPV-related head and neck cancer to patients	84 (87.5)	28 (100)	37 (92.5)	56 (94.9)	34 (91.9)	5.72 (0.221)
It is not necessary to tell patients that they have HPV because there's no implications for behaviour	11 (11.5)	2 (7.1)	3 (7.7)	1 (1.7)	2 (5.4)	5.37 (0.251)
My patients are not concerned about the cause of their cancer	4 (4.2)	0	0	2 (3.4)	2 (5.6)	3.30 (0.508)
It is not necessary to tell patients whether they have HPV because it doesn't change their clinical management	1 (1.0)	1 (3.6)	0	1 (1.7)	1 (2.7)	1.86 (0.761)
I am confident about initiating a discussion about HPV with a patient	77 (80.2)	25 (89.3)	32 (82.1)	23 (39.0)	15 (40.5)	50.04 (<0.001)
I am confident that I can explain HPV in a way that patients can understand	79 (82.3)	24 (85.7)	33 (82.5)	26 (44.1)	21 (56.8)	35.4 (<0.001)
I am confident that I can reassure patients that HPV is a result of normal sexual behaviour (n=174)	59 (74.7)	11 (100)	23 (82.1)	22 (75.9)	15 (55.6)	9.81 (0.044)

	Surgeons (n=96)	Oncologists (n=28)	Specialist nurses (n=40)	Speech and language therapists (n=59)	Other (n=37)	χ^2 (p value)
I am confident that I can deal with patients' questions and concerns when I talk to them about HPV	69 (71.9)	25 (89.3)	27 (67.5)	17 (28.8)	12 (32.4)	50.8 (<0.001)
Talking about HPV with a patient is not easy because it's about their sexual behaviour	34 (35.4)	13 (46.4)	14 (35.9)	33 (55.9)	12 (32.4)	8.56 (0.073)
Talking to a patient about HPV is embarrassing	7 (7.3)	2 (7.1)	3 (7.7)	11 (18.6)	6 (16.2)	6.65 (0.156)
I am not used to talking about sexual health with my patients	47 (49.0)	10 (35.7)	7 (17.9)	35 (59.3)	13 (35.1)	19.3 (0.001)
I would use a different approach than if the patient was alone	34 (35.4)	9 (32.1)	9 (23.1)	20 (34.5)	12 (32.4)	2.05 (0.726)
I would feel confident discussing the transmission of HPV	63 (65.6)	21 (75.0)	24 (61.5)	14 (23.7)	11 (29.7)	40.66 (<0.001)
I would feel comfortable talking about infidelity if this was raised	26 (27.1)	10 (35.7)	20 (51.3)	16 (27.1)	5 (13.5)	14.32 (<0.001)
I would feel comfortable talking about their sexual relationship	25 (26.0)	15 (53.6)	25 (64.1)	12 (20.3)	7 (18.9)	32.37 (<0.001)
I don't have enough information on HPV-related head and neck cancer	17 (17.7)	9 (32.1)	20 (50.0)	35 (60.3)	15 (40.5)	32.25 (<0.001)
HPV-related head and neck cancer is an evolving area so it's hard to keep up-to-date	35 (36.5)	9 (32.1)	20 (50.0)	43 (72.9)	12 (32.4)	25.86 (<0.001)
I might not have all the answers to patients' questions about HPV-related head and neck cancer	71 (74.0)	20 (71.4)	33 (82.5)	54 (93.1)	33 (89.2)	12.15 (0.016)

	Surgeons (n=96)	Oncologists (n=28)	Specialist nurses (n=40)	Speech and language therapists (n=59)	Other (n=37)	χ^2 (p value)
I don't want to pass judgement on patients' sexual behaviour	82 (86.3)	26 (92.9)	33 (82.5)	48 (81.4)	31 (86.1)	2.35 (0.672)
I don't have enough time to discuss HPV-related head and neck cancer	18 (18.8)	5 (17.9)	2 (5.3)	11 (18.6)	5 (13.5)	4.37 (0.36)
I don't think patients want to know about HPV-related head and neck cancer	1 (1.0)	1 (3.6)	0	0	1 (2.7)	3.38 (0.496)
I don't see any reason to discuss HPV with patients	0	0	0	1 (1.7)	2 (5.4)	7.89 (0.096)
Having a leaflet to pass onto patients would help me discuss HPV with them	77 (80.2)	22 (78.6)	39 (97.5)	56 (94.9)	31 (83.8)	12.75 (0.013)
Having a clear plan of what I was going to say would help me discuss HPV with patients	80 (83.3)	23 (82.1)	37 (92.5)	57 (96.6)	31 (83.8)	8.22 (0.084)
Have regular team updates	73 (76.0)	16 (57.1)	36 (90.0)	54 (91.5)	29 (78.4)	17.54 (0.002)
Have regular feedback of experiences with patients from colleagues	67 (69.8)	19 (67.9)	35 (89.7)	58 (98.3)	31 (83.8)	24.66 (<0.001)
Attend conferences	88 (91.7)	24 (85.7)	38 (95.0)	56 (94.9)	31 (83.8)	5.32 (0.256)
Attend further training	65 (67.7)	23 (82.1)	39 (97.5)	57 (96.6)	33 (89.2)	31.28 (<0.001)

n for items varies slightly due to missing data

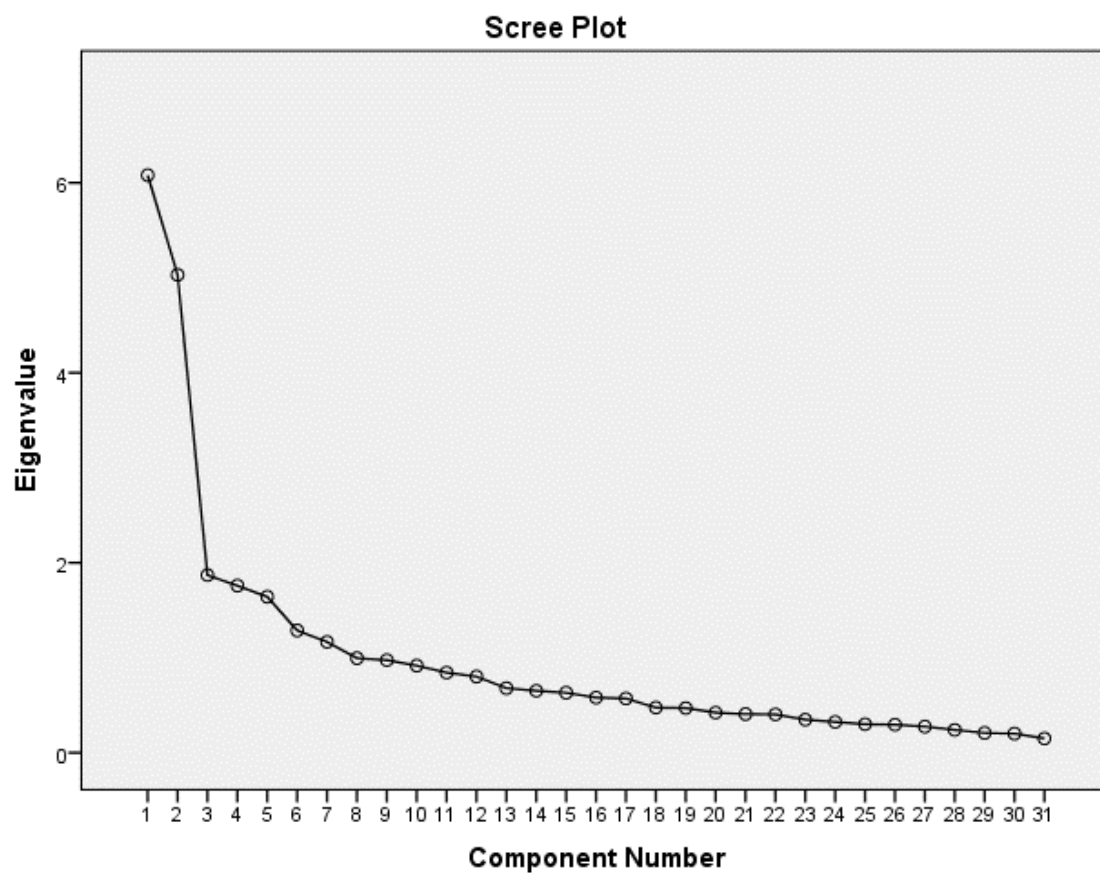
APPENDIX 7.7: COMPONENT CORRELATION MATRIX FOR OBLIQUE ROTATION**Component Correlation Matrix**

Component	1	2	3	4	5	6	7
1	1.000	-.088	.093	.153	-.196	.073	.273
2	-.088	1.000	.183	-.007	-.080	-.285	-.164
3	.093	.183	1.000	.039	-.244	-.176	.027
4	.153	-.007	.039	1.000	-.060	.098	.313
5	-.196	-.080	-.244	-.060	1.000	.182	-.104
6	.073	-.285	-.176	.098	.182	1.000	.218
7	.273	-.164	.027	.313	-.104	.218	1.000

Extraction Method: Principal Component Analysis.

Rotation Method: Oblimin with Kaiser Normalization.

APPENDIX 7.8: SCREE PLOT PRODUCED IN PRINCIPAL COMPONENTS ANALYSIS



APPENDIX 7.9: STUDY 4 – POST HOC TESTS FOR DIFFERENCES BETWEEN HEALTH PROFESSIONAL GROUPS ON EACH FACTOR

Multiple comparisons: Bonferroni

Dependent Variable	(I) What is your profession	(J) What is your profession	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Confidence in discussing HPV	Surgeon	Oncologist	-.15030	.15494	1.000	-.5891	.2885
		Specialist nurse	.14567	.13698	1.000	-.2422	.5336
		Other	.63271*	.13959	.000	.2374	1.0280
		Speech and Language Therapist	.99749*	.11997	.000	.6577	1.3372
	Oncologist	Surgeon	.15030	.15494	1.000	-.2885	.5891
		Specialist nurse	.29597	.17868	.989	-.2100	.8020
		Other	.78301*	.18069	.000	.2713	1.2947
		Speech and Language Therapist	1.14778*	.16600	.000	.6777	1.6179
	Specialist nurse	Surgeon	-.14567	.13698	1.000	-.5336	.2422
		Oncologist	-.29597	.17868	.989	-.8020	.2100
		Other	.48704*	.16555	.036	.0182	.9559
		Speech and Language Therapist	.85181*	.14938	.000	.4288	1.2748
	Other	Surgeon	-.63271*	.13959	.000	-1.0280	-.2374
		Oncologist	-.78301*	.18069	.000	-1.2947	-.2713
		Specialist nurse	-.48704*	.16555	.036	-.9559	-.0182
		Speech and Language Therapist	.36477	.15178	.170	-.0650	.7946
	Speech and Language Therapist	Surgeon	-.99749*	.11997	.000	-1.3372	-.6577
		Oncologist	-1.14778*	.16600	.000	-1.6179	-.6777
		Specialist nurse	-.85181*	.14938	.000	-1.2748	-.4288
		Other	-.36477	.15178	.170	-.7946	.0650

Ways to facilitate discussion of HPV	Surgeon	Oncologist	.08743	.11032	1.000	-.2250	.3998
		Specialist nurse	-.45974*	.09754	.000	-.7359	-.1835
		Other	-.12831	.09939	1.000	-.4098	.1531
		Speech and Language Therapist	-.45343*	.08497	.000	-.6940	-.2128
	Oncologist	Surgeon	-.08743	.11032	1.000	-.3998	.2250
		Specialist nurse	-.54716*	.12723	.000	-.9074	-.1869
		Other	-.21573	.12866	.948	-.5801	.1486
		Speech and Language Therapist	-.54086*	.11787	.000	-.8747	-.2071
	Specialist nurse	Surgeon	.45974*	.09754	.000	.1835	.7359
		Oncologist	.54716*	.12723	.000	.1869	.9074
		Other	.33143	.11788	.053	-.0024	.6652
		Speech and Language Therapist	.00630	.10600	1.000	-.2939	.3065
	Other	Surgeon	.12831	.09939	1.000	-.1531	.4098
		Oncologist	.21573	.12866	.948	-.1486	.5801
		Specialist nurse	-.33143	.11788	.053	-.6652	.0024
		Speech and Language Therapist	-.32513*	.10771	.028	-.6301	-.0201
	Speech and Language Therapist	Surgeon	.45343*	.08497	.000	.2128	.6940
		Oncologist	.54086*	.11787	.000	.2071	.8747
		Specialist nurse	-.00630	.10600	1.000	-.3065	.2939
		Other	.32513*	.10771	.028	.0201	.6301

Negative attitudes to discussing HPV	Surgeon	Oncologist	.07684	.11089	1.000	-.2372	.3909
		Specialist nurse	.32043*	.09807	.012	.0427	.5982
		Other	-.03982	.10093	1.000	-.3256	.2460
		Speech and Language Therapist	-.02316	.08548	1.000	-.2652	.2189
	Oncologist	Surgeon	-.07684	.11089	1.000	-.3909	.2372
		Specialist nurse	.24359	.12774	.577	-.1182	.6053
		Other	-.11667	.12994	1.000	-.4847	.2513
		Speech and Language Therapist	-.10000	.11834	1.000	-.4351	.2351
	Specialist nurse	Surgeon	-.32043*	.09807	.012	-.5982	-.0427
		Oncologist	-.24359	.12774	.577	-.6053	.1182
		Other	-.36026*	.11919	.028	-.6978	-.0227
		Speech and Language Therapist	-.34359*	.10642	.014	-.6450	-.0422
	Other	Surgeon	.03982	.10093	1.000	-.2460	.3256
		Oncologist	.11667	.12994	1.000	-.2513	.4847
		Specialist nurse	.36026*	.11919	.028	.0227	.6978
		Speech and Language Therapist	.01667	.10906	1.000	-.2922	.3255
	Speech and Language Therapist	Surgeon	.02316	.08548	1.000	-.2189	.2652
		Oncologist	.10000	.11834	1.000	-.2351	.4351
		Specialist nurse	.34359*	.10642	.014	.0422	.6450
		Other	-.01667	.10906	1.000	-.3255	.2922

Positive attitudes to discussing HPV	Surgeon	Oncologist	.01875	.10170	1.000	-.2692	.3067
		Specialist nurse	-.39625*	.08911	.000	-.6486	-.1439
		Other	-.05903	.09253	1.000	-.3211	.2030
		Speech and Language Therapist	-.13888	.07833	.774	-.3607	.0829
	Oncologist	Surgeon	-.01875	.10170	1.000	-.3067	.2692
		Specialist nurse	-.41500*	.11667	.004	-.7454	-.0846
		Other	-.07778	.11931	1.000	-.4156	.2601
		Speech and Language Therapist	-.15763	.10866	1.000	-.4653	.1501
	Specialist nurse	Surgeon	.39625*	.08911	.000	.1439	.6486
		Oncologist	.41500*	.11667	.004	.0846	.7454
		Other	.33722*	.10878	.022	.0292	.6452
		Speech and Language Therapist	.25737	.09698	.085	-.0172	.5320
	Other	Surgeon	.05903	.09253	1.000	-.2030	.3211
		Oncologist	.07778	.11931	1.000	-.2601	.4156
		Specialist nurse	-.33722*	.10878	.022	-.6452	-.0292
		Speech and Language Therapist	-.07985	.10014	1.000	-.3634	.2037
	Speech and Language Therapist	Surgeon	.13888	.07833	.774	-.0829	.3607
		Oncologist	.15763	.10866	1.000	-.1501	.4653
		Specialist nurse	-.25737	.09698	.085	-.5320	.0172
		Other	.07985	.10014	1.000	-.2037	.3634

Personal barriers to discussing HPV	Surgeon	Oncologist	-.06882	.14942	1.000	-.4920	.3543
		Specialist nurse	.38747*	.13333	.040	.0099	.7651
		Other	-.12071	.13462	1.000	-.5019	.2605
		Speech and Language Therapist	-.36074*	.11508	.019	-.6866	-.0348
	Oncologist	Surgeon	.06882	.14942	1.000	-.3543	.4920
		Specialist nurse	.45630	.17327	.090	-.0344	.9470
		Other	-.05188	.17426	1.000	-.5454	.4416
		Speech and Language Therapist	-.29192	.15965	.687	-.7440	.1602
	Specialist nurse	Surgeon	-.38747*	.13333	.040	-.7651	-.0099
		Oncologist	-.45630	.17327	.090	-.9470	.0344
		Other	-.50818*	.16068	.018	-.9632	-.0532
		Speech and Language Therapist	-.74822*	.14470	.000	-1.1580	-.3384
	Other	Surgeon	.12071	.13462	1.000	-.2605	.5019
		Oncologist	.05188	.17426	1.000	-.4416	.5454
		Specialist nurse	.50818*	.16068	.018	.0532	.9632
		Speech and Language Therapist	-.24004	.14589	1.000	-.6532	.1731
	Speech and Language Therapist	Surgeon	.36074*	.11508	.019	.0348	.6866
		Oncologist	.29192	.15965	.687	-.1602	.7440
		Specialist nurse	.74822*	.14470	.000	.3384	1.1580
		Other	.24004	.14589	1.000	-.1731	.6532

Need for more information	Surgeon	Oncologist	.03199	.10941	1.000	-.2778	.3418
		Specialist nurse	-.25729	.09587	.078	-.5288	.0142
		Other	-.07756	.09857	1.000	-.3567	.2016
		Speech and Language Therapist	-.48402*	.08472	.000	-.7239	-.2441
	Oncologist	Surgeon	-.03199	.10941	1.000	-.3418	.2778
		Specialist nurse	-.28929	.12552	.220	-.6447	.0662
		Other	-.10956	.12760	1.000	-.4709	.2518
		Speech and Language Therapist	-.51601*	.11722	.000	-.8480	-.1841
	Specialist nurse	Surgeon	.25729	.09587	.078	-.0142	.5288
		Oncologist	.28929	.12552	.220	-.0662	.6447
		Other	.17973	.11619	1.000	-.1493	.5088
		Speech and Language Therapist	-.22672	.10470	.313	-.5232	.0697
	Other	Surgeon	.07756	.09857	1.000	-.2016	.3567
		Oncologist	.10956	.12760	1.000	-.2518	.4709
		Specialist nurse	-.17973	.11619	1.000	-.5088	.1493
		Speech and Language Therapist	-.40645*	.10718	.002	-.7100	-.1030
	Speech and Language Therapist	Surgeon	.48402*	.08472	.000	.2441	.7239
		Oncologist	.51601*	.11722	.000	.1841	.8480
		Specialist nurse	.22672	.10470	.313	-.0697	.5232
		Other	.40645*	.10718	.002	.1030	.7100

Attitudes to talking about sexual relationships	Surgeon	Oncologist	-.32068	.19086	.942	-.8612	.2198
		Specialist nurse	-.67508*	.16874	.001	-1.1529	-.1972
		Other	-.03787	.17196	1.000	-.5248	.4491
		Speech and Language Therapist	.21866	.14700	1.000	-.1976	.6349
	Oncologist	Surgeon	.32068	.19086	.942	-.2198	.8612
		Specialist nurse	-.35440	.22012	1.000	-.9777	.2689
		Other	.28282	.22259	1.000	-.3475	.9131
		Speech and Language Therapist	.53935	.20393	.087	-.0381	1.1168
	Specialist nurse	Surgeon	.67508*	.16874	.001	.1972	1.1529
		Oncologist	.35440	.22012	1.000	-.2689	.9777
		Other	.63721*	.20394	.020	.0597	1.2147
		Speech and Language Therapist	.89374*	.18339	.000	.3744	1.4131
	Other	Surgeon	.03787	.17196	1.000	-.4491	.5248
		Oncologist	-.28282	.22259	1.000	-.9131	.3475
		Specialist nurse	-.63721*	.20394	.020	-1.2147	-.0597
		Speech and Language Therapist	.25653	.18635	1.000	-.2712	.7842
	Speech and Language Therapist	Surgeon	-.21866	.14700	1.000	-.6349	.1976
		Oncologist	-.53935	.20393	.087	-1.1168	.0381
		Specialist nurse	-.89374*	.18339	.000	-1.4131	-.3744
		Other	-.25653	.18635	1.000	-.7842	.2712

*. The mean difference is significant at the 0.05 level.

APPENDIX 8.1: ETHICAL APPROVAL FOR SET UP OF THE PAG

UCL RESEARCH ETHICS COMMITTEE
GRADUATE SCHOOL OFFICE



Dr Jo Waller
Health Behaviour Research Centre
Department of Epidemiology and Public Health
1-19 Torrington Place
UCL

2 July 2014

Dear Dr Waller

Notification of Ethical Approval

Project ID: 4577/002: The impact of a diagnosis of head and neck cancer: establishing a participatory advisory group

I am pleased to confirm that your study has been approved by the UCL Research Ethics Committee for the duration of the study i.e. **until September 2016**.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events

For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an

independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research.

Yours sincerely

A black rectangular box redacting the signature of Professor John Foreman.

Professor John Foreman
Chair of the UCL Research Ethics Committee

Cc:
Rachael Dodd, Applicant
Professor R.G.Watt

APPENDIX 8.2: ADVERT FOR RECRUITMENT TO THE PAG

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix A (Version 1, 19/06/2014)

The impact of a diagnosis of head and neck cancer: Establishing a Participatory Advisory Group

We are recruiting members for a Participatory Advisory Group (PAG) to help us try out research materials for studies exploring experiences of being diagnosed with head and neck cancer. A PAG will help us gain valuable perspectives from patients with your experience of head and neck cancers, and will ensure our research is worthwhile, relevant and carried out in the best possible way.

As part of the PAG you may be asked to:

- take part in practice interviews or focus groups
- comment on questionnaires to be used in larger studies
- advise on future research studies

To be able to take part you must:

- have been diagnosed with head and neck cancer
- be able to communicate in English
- be able to give informed consent

If you have had a diagnosis of head and neck cancer and would like to join our PAG, please read the information sheet and complete the questionnaire at:

<https://www.surveymonkey.com/s/88PCF5Q>

If you have any questions please contact Rachael Dodd at r.dodd@ucl.ac.uk or 020 7679 1723

APPENDIX 8.3: INFORMATION SHEET FOR THE PAG

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix C (Version 1, 19/06/2014)

Participant Information Sheet

Title of project: The impact of a diagnosis of head and neck cancer: Establishing a Participatory Advisory Group

We would like to invite you to join a participatory advisory group (PAG) of people who have been diagnosed with head and neck cancer. As part of the group, you may be asked to help try out questions for interview studies, comment on questionnaires and information materials developed for research studies, and have input into planning future research projects. We are particularly interested in people's beliefs about the causes of their head and neck cancer and how life might have changed since diagnosis. If we have a clear understanding of what people think and want to know about cancer then we will be able to develop cancer information in the best possible way. Having patients involved in our research helps make sure it is important and relevant.

Your participation is completely voluntary. Before you decide if you want to become a member of the PAG, please read the following information carefully. Ask us if there is anything that is unclear or if you would like more information.

What will I need to do?

If you agree to be a member of the PAG, you will need to complete a short online questionnaire giving us either your email address or phone number. Any data collected during this pilot work or PAG activity will be kept confidential and will only be available to the research team. For some studies, we may ask you if you have a partner who would be willing to help too. You will contribute to research that will help us understand more about people's beliefs about the causes of head and neck cancer and its impact on those diagnosed and their partners. You will be reimbursed for any travel expenses and for your time and inconvenience as and when you take part in any activities associated with the PAG.

If you decide to become a member of the PAG we will email or post you a copy of this information sheet and you will receive specific information sheets and consent forms for each pilot study or PAG activity. You are free to withdraw from the PAG at any time.

Who are the researchers?

We are from the Health Behaviour Research Centre at University College London. Our research is aimed at understanding the impact of being diagnosed with cancer and how we may support patients and members of their social support network with a diagnosis of cancer.

What will happen to the results?

Our research studies (which will be bigger than the pilot studies) will be written up as reports and may be published in academic journals and presented at conferences to other people interested in cancer prevention and communication. It will not be possible to identify you from any reports that are written. If you would like a copy of our results we will be happy to send them to you. An independent group called the University College London Research Ethics Committee has approved this study.

Thank you for taking time to read this. We hope you decide to take part.

Ms Rachael Dodd, Dr Jo Waller and Dr Laura Marlow
Telephone: 020 7679 1723
Email: r.dodd@ucl.ac.uk

For more information about the Health Behaviour Research Centre: <http://www.ucl.ac.uk/hbrc>

Department of Epidemiology and Public Health, University College London
Gower Street
LONDON WC1E 6BT

Project ID: 4577/002
Version 1 (19/06/2014)

APPENDIX 8.4: QUESTIONNAIRE FOR THE PAG

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix B (Version 1, 20/06/2014)

Participant Questionnaire

We would just like to ask some questions about you, your health and what types of work with the advisory group you would like to get involved in. All the information will be kept confidential and will be anonymised.

About you

1. What is your date of birth? (day/month/year)

___/___/___

2. Are you: Male ☐ Female ☐

3. How old were you when you left full-time education?

4. Which best describes your marital status?

- ☐ Single
☐ Married/Civil Partner
☐ Divorced/Person whose Civil Partnership has been dissolved
☐ Widowed/Surviving Civil Partner
☐ Separated
☐ Prefer not to say

5. What is your current employment status?

- ☐ Employed full-time
☐ Employed part-time
☐ Unemployed
☐ Self-employed
☐ Full-time homemaker

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- ☐ Retired
☐ Studying
☐ Disabled or too ill to work
☐ Carer

About your health

6. At what site was your primary cancer diagnosis?

- ☐ Oropharynx
☐ Lip
☐ Oral cavity
☐ Nasopharynx
☐ Hypopharynx
☐ Larynx
☐ Don't know
☐ Other (please specify) _____

7. When were you diagnosed? (month/year)

____/____

8. As part of your care did you have a HPV test?

- ☐ Yes
☐ No

If yes, was it positive or negative:

- ☐ Positive
☐ Negative
☐ Don't know

9. What treatment have you received?

- ☐ Radiation therapy (also called radiotherapy)
☐ Chemotherapy
☐ Both Radiation and Chemotherapy (Chemo-radiation)
☐ Surgery
☐ Other (please specify) _____

10. Have you ever smoked a cigarette, cigar or pipe?

- ☐ Yes
☐ No (**skip to Q12**)

11. Which of the following best describes your smoking habits?

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- ☐ Lifetime non-smoker (e.g. never really smoked cigarettes, just tried them once or twice)
- ☐ Regular smoker (e.g. smoking at least one cigarette per day)
- ☐ Occasional smoker (e.g. usually smoking less than one cigarette per week)
- ☐ Ex-smoker (e.g. stopped at least one year before today)

12. On average, how many cigarettes do/did you smoke per a day?

Number of cigarettes per day _____

13. How often do you usually have an alcoholic drink?

- ☐ Every day or almost every day
- ☐ About twice a week
- ☐ About once a week
- ☐ About once a fortnight
- ☐ About once a month
- ☐ Only a few times a year
- ☐ Never

About your involvement in the participatory advisory group

14. What types of activities would you be happy to be involved in? (Please tick all applicable)

- ☐ Taking part in interviews to help us develop our questions
- ☐ Commenting on questionnaires
- ☐ Attending meetings with the research team to discuss research protocols
- ☐ Taking part in focus groups
- ☐ Commenting on information developed by the research team
- ☐ Online only activities

Please provide your email address and/or telephone number so we can contact you about involvement in activities for the participatory advisory group:

Email address: _____

Telephone number: _____

APPENDIX 8.5: CONSENT FORM FOR THE PAG

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Appendix D (Version 1, 19/06/2014)

Consent Form

Title of Project: The impact of a diagnosis of head and neck cancer: Establishing a Participatory Advisory Group

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 4577/002

Please complete this form after you have read the Information Sheet. Please tick each box to indicate you agree with the statement. If you have any questions about the Information Sheet, please ask the researcher before you to decide whether to take part.

Thank you for your interest in taking part in this project.

Participant's Statement

I TYPE NAME

- ☐ have read the Information Sheet, and understand what being part of the participatory advisory group involves. ☐
- ☐ understand that if I decide at any time that I no longer wish to be a member of the participatory advisory group, I can notify the researchers and withdraw immediately. ☐
- ☐ understand I will have the opportunity to consent to each piece of pilot work or PAG activity I choose to be involved in ☐
- ☐ consent to the processing of my personal information for the purposes of my role in the participatory advisory group. ☐
- ☐ understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998. ☐
- ☐ agree that the research named above has been explained to me to my satisfaction and I agree to be a part of the participatory advisory group and contribute to pilot research. ☐

Signed:
TYPE NAME

Date:

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APPENDIX 8.6: STUDY 5 - NHS ETHICS APPROVAL

**NRES Committee London - South East**

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7109
Fax: 0161 625 7919

09 June 2015

Dr Jo Waller
Epidemiology and Public Health, UCL
Gower Street
London
WC1E 6BT

Dear Dr Waller

Study title: The psychosocial impact of a HPV-related head and neck cancer diagnosis on patients and their partners
REC reference: 15/LO/0803
IRAS project ID: 144658

Thank you for your submission of 03 June 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Sub Committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Margaret Hutchinson, nrescommittee.london-southeast@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

With regards to the sensitive nature of the study, the Committee have strongly recommended that the additional following changes are also made to the Participant Information Sheets, and regret not having made these points in the original provisional opinion letter. The Committee would like to apologise for this oversight, and although have been happy to issue the favourable opinion in response to your submission, would like to ask that you strongly consider making these changes as these additional points have not been clearly explained in the information sheets and are clearly laid out in the protocol.

- 1) Patient Information Sheet: In the section explaining Partner involvement make explicit that you will be asking for consent from the patient to approach the Partner, and for the Partner's contact details. If there is no Partner, or Partner does not consent, interview with Patient can still go ahead.
- 2) Patient Consent Form: To include a point consenting to provide Partner contact details and for the research team to approach the Partner. In addition that no other approach will be made to the Partner and that their contact details will be destroyed at the conclusion of their involvement.
- 3) Partner Information Sheet: Explain that consent has been provided by the patient for approach and invitation and that their contact details will be destroyed at the conclusion of their involvement.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra_studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover letter]	1.0	16 April 2015
Covering letter on headed paper [Cover letter]		03 June 2015
Interview schedules or topic guides for participants [Patient interview topic guide]	1.0	23 September 2014
Interview schedules or topic guides for participants [Partner interview topic guide]	1.0	23 September 2014
Letters of invitation to participant [Invitation letter]	2.0	02 June 2015
Letters of invitation to participant [Second invitation letter]	2.0	02 June 2015
Non-validated questionnaire [Patient demographic questionnaire]	1.0	24 September 2014
Non-validated questionnaire [Partner demographic questionnaire]	1.0	24 September 2014
Participant consent form [Patient consent form]	2.0	02 June 2015
Participant consent form [Partner consent form]	2.0	02 June 2015
Participant information sheet (PIS) [Patient information sheet]	2.0	02 June 2015
Participant information sheet (PIS) [Partner information sheet]	2.0	02 June 2015
REC Application Form [REC_Form_23042015]		23 April 2015
Referee's report or other scientific critique report [Educational supervisor review]	1.0	23 October 2014
Research protocol or project proposal [Research protocol]	2.0	02 June 2015
Summary CV for Chief Investigator (CI) [CV for Chief Investigator]	1.0	15 April 2015
Summary CV for student [Summary CV for student]	1.0	15 April 2015
Summary CV for supervisor (student research) [CV for second academic supervisor]	1.0	15 April 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study flowchart]	1.0	24 September 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/LO/0803	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



pp
Professor David Caplin
Chair

Email: nrescommittee.london-southeast@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Clara Kalu, University College London Hospitals NHS Foundation Trust

APPENDIX 8.7: STUDY 5 – TOPIC GUIDE FOR PATIENT INTERVIEWS

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Interview Topic guide – Patients

Introduction

- Open with an introduction to self and the study, giving background and aims of the study – explain a university study, not the NHS
- Tell the participant how long you expect the interview to take (between 30 minutes to an hour) and explain that the interview will be tape recorded
- Explain about confidentiality, and the use of the data
- Explain don't need to talk about anything uncomfortable with and no right/wrong answers
- Any questions?

Patient's experience

- Ask about patients experience of being diagnosed – this is an open ended question to enable the patient to talk freely about their experiences

Prompts:

Symptoms - Symptom recognition and how long before went to a HCP
Disclosing symptoms to anyone

Diagnosis - Who/how/what/when told
Any difficulties/anxieties
Involved in any care/treatment decisions?
Alone or with a partner?
Referred for any support? (counselling needs, QoL, psych treatment)

IF HPV mentioned:

What was talked about
How did you feel

IF HPV NOT mentioned:

Did the health professional mention the cause of your cancer at all/ what did the health professional say about the cause of your cancer
If so, how did you feel

Psychosocial – Initial feelings

Disclosure to partner/others
Reactions of partner/others
Adjustments/coping/impact on daily life (physical, psychological, social, functional)
Anything to help you cope better?
Changes to relationship?
Effect on others
Feelings about the future

Information needs – any research prior to diagnosis

Amount of information received
Lacking any information?
Look elsewhere for information? If so, where, what helpful/unhelpful
Were you given any written information? Need for it?

Closing the interview

Any other comments, issues or suggestions that haven't been raised?

- Thank interviewee
- Reassure about confidentiality
- Give debrief, repeating the aims of the study and leaving details of available support
- Ask if happy to be re-contacted later for future research studies

Interview topic guide (patient)

Version: 1.0, 23/09/2014

APPENDIX 8.8: STUDY 5 – TOPIC GUIDE FOR PARTNER INTERVIEWS

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE



Interview Topic guide – Partners

Introduction

- Open with an introduction to self and the study, giving background and aims of the study – explain a university study, not the NHS
- Tell the participant how long you expect the interview to take (between 30 minutes to an hour) and explain that the interview will be tape recorded
- Explain about confidentiality, and the use of the data
- Explain don't need to talk about anything uncomfortable with and no right/wrong answers
- Any questions?

Partners experience

- Ask about partners experience around the diagnosis – this is an open ended question to enable the partner to talk freely about their experiences

Prompts:

Symptoms - Did your partner disclose their symptoms to you
How long before went to a HCP

Diagnosis - IF present at the diagnosis
Who/how/what/when told
Any difficulties/anxieties
Involved in care/treatment decisions
Referred for any support? (counselling needs, QoL, psych treatment)
IF NOT present at diagnosis:
What did patient say about diagnosis - any questions or concerns, information seeking behaviours at this stage?

IF HPV mentioned:
What was talked about
How did you feel

IF HPV NOT mentioned:
Did the health professional mention the cause of your partners cancer at all?
If so, how did you feel

Psychosocial – Initial feelings
Disclosure to others
Reactions of others
Adjustments/coping/impact on daily life (physical, psychological, social)
Anything to help you cope better?
Changes to relationship?
Effect on others
Feelings about the future

Information needs – any research prior to diagnosis
Amount of information received
Lacking any information?
Look elsewhere for information? If so, where, what helpful/unhelpful
Were you given any written information? Need for it?

Closing the interview

- Any other comments, issues or suggestions that haven't been raised?
- Thank interviewee
- Reassure about confidentiality
- Give debrief, repeating the aims of the study and leaving details of available support
- Ask if happy to be re-contacted later for future research studies

Interview topic guide (partner)
Version: 1.0, 23/09/2014

APPENDIX 8.9: STUDY 5 – EXAMPLE INVITATION LETTER



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Public Health
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WC1E 6BT
Email: r.dodd@ucl.ac.uk
Tel: 0207 679 8254
Fax: 0207 679 8354
Website: <http://www.ucl.ac.uk/hbrc>



Aintree University Hospital NHS Foundation
Trust
Lower Lane
Liverpool
L9 7AL

Direct line: 0151 529 5259

Email: T.M.Jones@liverpool.ac.uk
Website: <http://www.aintreehospitals.nhs.uk/>

DATE

Dear [insert name]

Re: Invitation to take part in research exploring the impact of a diagnosis of HPV-related head and neck cancer

Aintree University Hospital NHS Foundation Trust is working with University College London to help them recruit participants to take part in an interview study exploring experiences of being diagnosed with HPV-related head and neck cancer. The study aims to understand how the diagnosis of HPV-related head and neck cancer may impact upon a patient and their partner's life. This study is being done as part of a Medical Research Council funded PhD.

I am writing to you because I think you may be eligible to take part in the study.

Taking part would involve an interview which can be carried out either face-to-face or over the telephone. This is likely to last between 30 and 60 minutes. The interviews will be recorded and transcribed, with all transcripts being made anonymous. What you say in these interviews will not affect any future care you may receive. You do not have to take part and if you choose not to, this will not compromise your care. You will have the right to withdraw at any point during the study.

For more information about the study and what will happen if you decide to take part, please see the information sheet enclosed.

If you are interested in taking part in this study please complete the enclosed reply slip and consent form and return it to us in the FREEPOST envelope within 2 WEEKS of the date of this letter. The researcher, Rachael Dodd, will contact you to arrange an interview.

Thank you for your time and help.

Yours sincerely,

Dr Terry Jones

Invitation letter
Version: 2.0, 02/06/2015
REC Number: 15/LO/0803

Page 1 of 2

I am happy for Rachael Dodd to contact me about an interview study on head and neck cancer.

My name is _____

My phone number is _____

My email address is _____

Preferred method of contact: Phone ☐ Email ☐

Good times/days to contact me: _____

Please **return** this reply form in the **FREEPOST envelope**.

You can also contact **Rachael Dodd** on: 020 7679 8254 or email: r.dodd@ucl.ac.uk

APPENDIX 8.10: STUDY 5 – EXAMPLE PATIENT INFORMATION SHEET



Participant Information Sheet

Title of project: Exploring the experiences of a diagnosis of HPV-related head and neck cancer

We would like to invite you to take part in a research study about your experience of being diagnosed with human papillomavirus (HPV)-related head and neck cancer. We are interested in your thoughts about your cancer and how your life might have changed since your diagnosis. Before you decide if you want to take part in this research, please read the following information carefully to understand why the research is being done and what it would involve for you. Ask us if there is anything that is unclear or if you would like more information.

What is the purpose of the study?

This study is being done as part of a Medical Research Council funded PhD and the aim of the study is to explore the experiences of patients being diagnosed with HPV-related head and neck cancer and how your life might have changed since your diagnosis. We are also interested in the experiences of patients' partners and how their lives might have changed since your diagnosis with cancer. If we have a clear understanding of people's beliefs about cancer then we will be able to develop cancer information in the best possible way.

Why have I been invited?

You have been invited as your medical records show that you were diagnosed with HPV-related head and neck cancer at least one year ago. We are hoping to recruit up to 20 participants into the study.

Do I have to take part?

Your participation is completely voluntary. If you decide to take part you may keep this information sheet with the researcher's contact information if you have any questions. You are free to withdraw at any time without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you agree to take part in this research project you will need to complete the enclosed consent form and return it in the FREEPOST envelope provided, along with your contact details so that we can contact you. You will be given a signed copy of the consent form to keep. The researcher will contact you to answer any questions you may have and arrange a one-off interview which will take between 30 and 60 minutes. This interview can either be carried out face-to-face at a convenient location for you, or as a telephone interview. The researcher will ask you where you would like the interview to take place when arranging the interview. The interview will be recorded and transcribed verbatim. The transcript will be anonymised so that any details that could identify you will be removed. The researcher will also ask for your consent to approach your partner about taking part in the study and also for your partner's contact details. If you do not have a partner, you do not wish us to contact your partner, or your partner does not consent to take part in the study, your interview can still go ahead.

Each interview will be completely confidential, and we will not discuss your interview with your partner or your partner's interview with you. The content of the first interview will not influence what is discussed in the second interviews. Contact details of services offering help and support to cancer patients will be available to both yourself and your partner if any concerns are identified during the interviews.

What will I have to do?

If you agree to take part in this research project you will take part in a one-off interview with the researcher lasting between 30 and 60 minutes. The interview will involve discussion around HPV and how your life may have changed since your diagnosis. We would also like your consent to get some information from your medical records such as your diagnosis and date of diagnosis. Your name will not be attached to this information. We will also ask you to complete a short questionnaire asking a few questions about you.

What are the possible benefits and disadvantages of participating?

By participating you will be contributing to important research that helps us understand more about people's beliefs about cancer and how this may impact both those diagnosed and their partners. As the interview will involve talking about your experiences of being diagnosed with cancer, it may draw on some experiences that were upsetting.

What will happen if I don't want to carry on with the study?

If you decide that you do not wish to be part of the study after a date for the interview has been arranged, contact the research team and they can cancel your appointment and withdraw you from the study. If you choose to no longer take part after the interview has taken place, please contact us within 24 hours and all identifiable information will be destroyed and removed from the study until the point of the data being published. If you lose the capacity to consent to taking part, all identifiable information will be destroyed and removed from the study until the point of the data being published.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask a member of the research team (contact details below) if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Dr Jo Waller who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Will my taking part in this study be kept confidential?

All information that is collected during the interview will be kept confidential. All recordings are kept securely for 20 years and will only be accessible to the research team. Our procedures for storage, processing, handling, and destroying the information you give us are in line with the Data Protection Act (1998). After 20 years all information will be securely destroyed.

What will happen to the results of the research study?

The interviews will be very valuable to our research, will be written up as a report and may be published in academic journals and presented at conferences to other people interested in cancer prevention and communication. Your name will not be attached to your recording or transcript and it will not be possible to identify you from any reports that are written. If you would like a copy of our results we will be happy to send them to you.

Who is organising and funding the research?

We are from the Health Behaviour Research Centre at University College London. Our research is aimed at understanding the impact of being diagnosed with cancer and how we may support patients and members of their social support network with a diagnosis of cancer.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by South East London Research Ethics Committee, reference 15/LO/0803.

If you require any further support or information, you may find it useful to contact the hospital Patient Advise and Liaison Service on 0151 529 3287 or at complaints@aintree.nhs.uk.

Thank you for taking time to read this. We hope you decide to take part.

Ms Rachael Dodd, Dr Jo Waller and Dr Laura Marlow
Health Behaviour Research Centre
Department of Epidemiology and Public Health
University College London
Gower Street
London WC1E 6BT
Telephone: 020 7679 8254 (Rachael Dodd)
Email: r.dodd@ucl.ac.uk
j.waller@ucl.ac.uk
l.marlow@ucl.ac.uk

For more information about the Health Behaviour Research Centre: <http://www.ucl.ac.uk/hbrc>

APPENDIX 8.11: STUDY 5 – EXAMPLE PATIENT CONSENT FORM



Aintree University Hospital **NHS**
NHS Foundation Trust

Centre Number: 001

Patient Identification Number:

Consent Form

Title of Project: Exploring the experiences of a diagnosis of HPV-related head and neck cancer

Name of Researcher: Rachael Dodd

Please complete this form after you have read the Information Sheet. If you have any questions about the Participant Information Sheet, please ask the researcher before you decide whether to take part.

Please initial box

1. I confirm that I have read and understand the information sheet dated 09/06/2015 (version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected. I understand that identifiable data being destroyed but data not identifiable to the research team may be retained.
3. I consent to providing my partner's contact details to the research team and to them approaching my partner. I understand that no further approach will be made to my partner and that their contact details will be destroyed at the conclusion of your involvement in the study. (optional)
4. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from University College London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I understand that my interview will be audio recorded and I consent to use of this material as part of the study.
6. I consent to the processing of my personal information for the purposes of this research study and that that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
7. I agree to take part in the above study.

☐
☐
☐
☐
☐
☐
☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file

Consent form (Patient)
Version: 3.0, 09/06/2015
REC Number: 15/LO/0803

Page 1 of 1

APPENDIX 8.12: STUDY 5 – EXAMPLE PATIENT QUESTIONNAIRE



Centre Number: 001

Patient Identification Number:

Aintree University Hospital **NHS**
NHS Foundation Trust

Participant Questionnaire

We would just like to ask some questions about you. All the information will be kept confidential and will be anonymised.

About you

1. What is your date of birth? (day/month/year)

____ / ____ / ____

2. Are you: Male ☐ Female ☐

3. How old were you when you left full-time education?

4. Which best describes your marital status?

- ☐ Single
☐ Married/Civil Partner
☐ Divorced/Person whose Civil Partnership has been dissolved
☐ Widowed/Surviving Civil Partner
☐ Separated
☐ Prefer not to say

5. What is your current employment status?

- ☐ Employed full-time
☐ Employed part-time
☐ Unemployed
☐ Self-employed
☐ Full-time homemaker
☐ Retired
☐ Studying
☐ Disabled or too ill to work
☐ Carer

6. What is your ethnic group?

- ☐ White British
- ☐ White Irish
- ☐ Other White background
- ☐ Black British
- ☐ Black Caribbean
- ☐ Black African
- ☐ White Asian
- ☐ Chinese
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ Other
- ☐ Prefer not to say

About your health

7. As part of your care did you have a HPV test?

- ☐ Yes
- ☐ No

If yes, was it positive or negative:

- ☐ Positive
- ☐ Negative
- ☐ Don't know

Involvement in future research

8. Would you be willing to discuss taking part in future research studies at the end of your interview?

- ☐ Yes
- ☐ No
- ☐ Unsure

APPENDIX 8.13: STUDY 5 – EXAMPLE SECOND INVITATION LETTER



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Tel: 0207 679 8254
Fax: 0207 679 8354
Website: <http://www.ucl.ac.uk/hbrc>



Aintree University Hospital NHS
Foundation Trust
Lower Lane
Liverpool
L9 7AL

Direct line: 0151 529 5259

Email: T.M.Jones@liverpool.ac.uk
Website: <http://www.aintrreehospitals.nhs.uk/>

DATE

Dear [insert name]

Re: Invitation to take part in research exploring the impact of a diagnosis of HPV-related head and neck cancer

A few weeks ago I wrote to you about taking part in the above study. So far, not everyone who was invited to take part has responded. I am, therefore, sending you another copy of the information pack and FREEPOST return envelope, in case the first copies have been mislaid.

Just to remind you, Aintree University Hospital NHS Foundation Trust is working with University College London to help them recruit participants to take part in an interview study exploring experiences of being diagnosed with HPV-related head and neck cancer. The study aims to understand how the diagnosis of HPV-related head and neck cancer may impact upon a patient and their partner's life. This study is being done as part of a Medical Research Council funded PhD.

I am writing to you because I think you may be eligible to take part in the study.

Taking part would involve an interview which can be carried out either face-to-face or over the telephone. This is likely to last between 30 and 60 minutes. The interviews will be recorded and transcribed, with all transcripts being made anonymous. What you say in these interviews will not affect any future care you may receive. You will have the right to withdraw at any point during the study.

For more information about the study and what will happen if you decide to take part, please see the information sheet enclosed.

If you are interested in taking part in this study please complete the enclosed reply slip and consent form and return it to us in the FREEPOST envelope within 2 WEEKS of the date of this letter. The researcher, Rachael Dodd, will contact you to arrange an interview.

If you have already sent your consent form and reply slip back, or if you do not wish to respond, please ignore this second invitation and accept our apologies for any inconvenience caused.

Thank you for your time and help.

Yours sincerely,

Dr Terry Jones

Second invitation letter
Version: 2.0, 02/08/2015
REC number: 15/LO/0803

Page 1 of 2

I am happy for Rachael Dodd to contact me about an interview study on head and neck cancer.

My name is _____

My phone number is _____

My email address is _____

Preferred method of contact: Phone ☐ Email ☐

Good times/days to contact me: _____

Please **return** this reply form in the **FREEPOST envelope**.

You can also contact **Rachael Dodd** on: 020 7679 8254 or email: r.dodd@ucl.ac.uk

APPENDIX 8.14: STUDY 5 – EXAMPLE PARTNER INFORMATION SHEET



Aintree University Hospital **NHS**
NHS Foundation Trust

Participant Information Sheet

Title of project: Exploring the experiences of a diagnosis of HPV-related head and neck cancer

We would like to invite you to take part in a research study about your experience of your partner being diagnosed with human papillomavirus (HPV)-related head and neck cancer. We are interested in your thoughts about your partner's cancer and how your life might have changed since your partner's diagnosis. Your participation is completely voluntary. Before you decide if you want to take part in this research, please read the following information carefully. Ask us if there is anything that is unclear or if you would like more information.

What is the purpose of the study?

This study is being done as part of a Medical Research Council funded PhD and the aim of the study is to explore the experiences of patients being diagnosed with HPV-related head and neck cancer and how your life might have changed since your diagnosis. We are also interested in the experiences of patients' partners and how their lives might have changed since your diagnosis with cancer. If we have a clear understanding of people's beliefs about cancer then we will be able to develop cancer information in the best possible way.

Why have I been invited?

You have been invited as you have a partner who was diagnosed with HPV-related head and neck cancer at least one year ago. We are hoping to recruit up to 20 participants into the study. Your partner has provided consent for us to contact you.

Do I have to take part?

Your participation is completely voluntary. If you decide to take part you may keep this information sheet with the researcher's contact information if you have any questions. You are free to withdraw at any time without giving a reason.

What will happen to me if I take part?

If you agree to take part in this research project you will need to complete the enclosed consent form which will be collected at the interview. The researcher will contact you to arrange an interview which will take between 30 and 60 minutes. We will aim to carry out your interview on the same day as your partner. This interview can either be carried out face-to-face at a convenient location for you, or as a telephone interview. The researcher will ask you where you would like the interview to take place when arranging the interview. The interview will be recorded and transcribed verbatim. The transcript will be anonymised so that any details that could identify you will be removed. We will also ask you to complete a short questionnaire asking a few questions about you. Your contact details will be destroyed at the conclusion of your involvement in the study.

Each interview will be completely confidential, and we will not discuss your interview with your partner or your partner's interview with you. The content of the first interview will not influence what is discussed in the second interview. Contact details of services offering help and support to cancer

patients will be available to both yourself and your partner if any concerns are identified during the interviews.

What will I have to do?

If you agree to take part in this research project you will take part in a one-off interview with the researcher lasting between 30 and 60 minutes. The interview will involve discussion around HPV, ask about your partner's cancer and how your life may have changed since your partner's diagnosis. We will also ask you to complete a short questionnaire asking a few questions about you.

What are the benefits and disadvantages of participating?

By participating you will be contributing to important research that helps us understand more about people's beliefs about cancer and how this may impact both those diagnosed and their partners. As the interview will involve talking about your experiences of your partner being diagnosed with cancer, it may draw on some experiences that were upsetting.

What will happen if I don't want to carry on with the study?

If you decide that you do not wish to be part of the study after a date for the interview has been arranged, contact the research team and they can cancel your appointment and withdraw you from the study. If you choose to no longer take part after the interview has taken place, please contact us within 24 hours and all identifiable information will be destroyed and removed from the study until the point of the data being published. If you lose the capacity to consent to taking part, all identifiable information will be destroyed and removed from the study until the point of the data being published.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask a member of the research team (contact details below) if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Dr Jo Waller who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Will my taking part in this study be kept confidential?

All information that is collected during the interview will be kept confidential. All recordings are kept securely for 20 years and will only be accessible to the research team. Our procedures for storage, processing, handling, and destroying the information you give us are in line with the Data Protection Act (1998). After 20 years all information will be securely destroyed.

What will happen to the results of the research study?

The interviews will be very valuable to our research, will be written up as a report and may be published in academic journals and presented at conferences to other people interested in cancer prevention and communication. Your name will not be attached to your recording or transcript and it will not be possible to identify you from any reports that are written. If you would like a copy of our results we will be happy to send them to you.

Who is organising and funding the research?

We are from the Health Behaviour Research Centre at University College London. Our research is aimed at understanding the impact of being diagnosed with cancer and how we may support patients and members of their social support network with a diagnosis of cancer.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by South East London Research Ethics Committee, reference 15/LO/0803.

If you require any further support or information, you may find it useful to contact the hospital Patient Advise and Liaison Service 0151 529 3287 or at complaints@aintree.nhs.uk.

Thank you for taking time to read this. We hope you decide to take part.

Ms Rachael Dodd, Dr Jo Waller and Dr Laura Marlow
Health Behaviour Research Centre
Department of Epidemiology and Public Health
University College London
Gower Street
London WC1E 6BT
Telephone: 020 7679 8254 (Rachael Dodd)
Email: r.dodd@ucl.ac.uk

For more information about the Health Behaviour Research Centre: <http://www.ucl.ac.uk/hbrc>

APPENDIX 8.15: STUDY 5 – EXAMPLE PARTNER CONSENT FORM



Centre Number: 001

Participant Identification Number:

Consent Form

Title of Project: Exploring the experiences of a diagnosis of HPV-related head and neck cancer

Name of Researcher: Rachael Dodd

Please complete this form after you have read the Information Sheet. If you have any questions about the Participant Information Sheet, please ask the researcher before you to decide whether to take part.

Please initial box

1. I confirm that I have read and understand the information sheet dated 09/06/15 (version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected. I understand that identifiable data being destroyed but data not identifiable to the research team may be retained. ☐
3. I understand that my interview will be audio recorded and I consent to use of this material as part of the study. ☐
4. I consent to the processing of my personal information for the purposes of this research study and that that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998. ☐
5. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file

Consent form (Partner)
Version: 2.0, 02/06/2015
REC Number: 15/LO/0803

Page 1 of 1

APPENDIX 8.16: STUDY 5 – EXAMPLE PARTNER QUESTIONNAIRE



Centre Number: 001

Participant Identification Number:

Participant Questionnaire

We would just like to ask some questions about you. All the information will be kept confidential and will be anonymised.

About you

1. What is your date of birth? (day/month/year)

___ / ___ / ___

2. Are you: Male ☐ Female ☐

3. How old were you when you left full-time education?

4. Which best describes your marital status?

- ☐ Single
☐ Married/Civil Partner
☐ Divorced/Person whose Civil Partnership has been dissolved
☐ Widowed/Surviving Civil Partner
☐ Separated
☐ Prefer not to say

5. What is your current employment status?

- ☐ Employed full-time
☐ Employed part-time
☐ Unemployed
☐ Self-employed
☐ Full-time homemaker
☐ Retired
☐ Studying
☐ Disabled or too ill to work
☐ Carer

Participant questionnaire
 Version: 1.0, 24/09/14
 REC number: 15/LO/0803

6. What is your ethnic group?

- ☐ White British
- ☐ White Irish
- ☐ Other White background
- ☐ Black British
- ☐ Black Caribbean
- ☐ Black African
- ☐ White Asian
- ☐ Chinese
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ Other
- ☐ Prefer not to say

Involvement in future research

7. Would you be willing to discuss taking part in future research studies at the end of your interview?

- ☐ Yes
- ☐ No
- ☐ Unsure

APPENDIX 9.1: STUDY 6 – PROJECT BRIEF

Resonant[™]

020 7498 8055
www.resonant.agency
info@resonant.agency
@Resonant_agency



Toolkit for people with throat and neck cancer caused by HPV

Helping clinicians explain a diagnosis of throat and neck cancer caused by the human papilloma virus (HPV)

**Proposal prepared for
Rachael Dodd
Health Behaviour Research Centre**

23 November 2015
Our ref: 1562

Registered Address: c/o Montgomery Swann, Scott's Sufferance Wharf, 1 Mill Street, London, SE1 2DE
Company registration number 05088600, VAT number 844 0049 48



1./ Background

UCL Health Behaviour Research Centre (HBRC) has been carrying out research into the needs of people who are diagnosed with throat and neck cancer caused by Human papilloma virus (HPV).

The research has demonstrated that:

- Good quality, easily accessible information about HPV as a cause of throat and neck cancer is scarce and not readily available
- There are a number of misconceptions about HPV which lead to embarrassment and stigma in some people when they discover their throat and neck cancer is caused by the virus
- There are some specific clinical issues that are pertinent to throat and neck cancer caused by HPV, including an improved prognosis in comparison to other throat and neck cancers
- Clinicians sometimes struggle to address the issues and questions that patients have, including many of their personal concerns when learning that HPV is the cause of their cancer.

2./ Objectives

The objectives of the project are to:


- Create a toolkit to facilitate the initial revelation that the throat and neck cancer is caused by HPV, so that both the person with the diagnosis (and their friend or family member if present) and the clinician have a better experience of the appointment
- To provide the person with the diagnosis with key information about what the diagnosis means for them
- To address some of the personal stigma attached to learning that HPV is the cause of the cancer.

The toolkit needs to be in a format that will be useful to the person with the new diagnosis (their friends and family) and also to the clinician. Current understanding indicates that the toolkit will need to be made available as a PDF for clinicians to print off during the appointment, and also available in a pre-printed format.

3./ Your requirement and costs

The following activities reflect our understanding of the project and our recommended approach.

- Target audience – 40 to 65 year olds – generally well-educated, with a bias on men
- Format – to work both as PDF and also pre-printed – currently based on 6 page A4
- Initial content to be provided by UCL (to be copy written by Resonant)
- Initial design drafts by mid-January (to be tested in focus groups in February)




Requirement	Includes	Cost
Review existing research	<ul style="list-style-type: none"> Review research provided to better understand the issue from the perspective of people with the new diagnosis – in particular to understand their needs and preferences for information, tone, style, etc Additional recommendations on format and content <p>Director – 1 day</p>	N/A
Copywriting	<ul style="list-style-type: none"> Review of content received from UCL Comments on content in light of review above Copy editing for tone and style Copy editing to fit designs (below) <p>Copywriter – 2 days</p>	650.00
Creative development	<ul style="list-style-type: none"> Graphic design of materials, including running out copy Copy editing to fit designs Up to 5 stock photos Visual language for the guide Amend cycle (up to 2 iterations) <p>Designer – 3 days Stock photography (5)</p>	2,175.00
Account management	<ul style="list-style-type: none"> Project management In project communications <p>Account manager – 0.5 day</p>	300.00
Total		3,125.00

Note:

- Prices are exclusive of VAT
- Illustrations are not included (eg of anatomy)

3./ Estimated schedule

The following schedule can be amended as needed.



	30-Nov Week 1	07-Dec Week 2	14-Dec Week 3	21-Dec Christmas	28-Dec Break	04-Jan	11-Jan Week 4	18-Jan Week 5	25-Jan Week 6
Receive content from UCL									
Copy writing									
Review copy									
Creative design									
Review									
Final amends									

4./ Assumptions

- This contract is based upon our understanding of the project
- Allowed for 2 sets of amends on copy and design. Additional changes may require additional resources.
- Alterations, outside the scope of this contract, will be quoted for separately
- Delivery to one UK address is included with the costs.

This proposal is based upon our understanding of the project. Alterations, outside the scope of this proposal, will be quoted for separately. Unless stated, this proposal does not include photographic images, illustrations or maps. All goods remain the property of Resonant Media Ltd until paid for in full. This estimate is valid for 30 days and is subject to our standard terms of business. The above prices are subject to VAT where applicable. For a full copy of our terms of conditions, please call 020 7498 8055 or email info@resonant.agency

APPENDIX 9.2: STUDY 6 – FEEDBACK FROM EXPERTS

Expert	Page	Section	Comment
Virologist	2	What is HPV?	Insert scrotum skin (balls) after penis
	3	How did I get HPV?	I would rephrase to read oral sex and probably open mouth kissing since the real risk for transmission is the tongue/oral skin on the penile skin
	4	Is my partner at risk of HPV?	Change 'can be passed through skin-to-skin' to 'is passed through skin-to-skin'
	5	Should I be vaccinated against HPV?	Rather cautious - the evidence is that vaccination prevents persistent infection in the oral cavity and oropharynx. The statement that we do not know if it prevents cancer is correct, but it does prevent infection
	7	There is no need to change your behaviour	'Using condoms for all sexual behaviours' - insert 'especially with new partners'
HNC surgeon	2	What is HPV?	Change balls to testes (all other terms are medical)
	2	Can they cause cancer?	Maybe a bit confusing - you give e.g. 6 and 11 and give examples of 2 and 1
	2	What is HPV? 'Most sexually active...'	Maybe expand this to highlight that the vast majority of us will clear the infection, a small number will set up a chronic infective/inflammatory state while only a very small % of us will go on to get cancer
	2	What is HPV? 'All 12-13 year old...'	Is this true? Are we not currently using the bivalent vaccine? I may be wrong here, I can never remember!
	3	What is HPV? 'Men who have sex with men...'	Has this been formally agreed by the JCVI yet - I was of the opinion that official sign off was awaited? Again, I may be wrong?
	2	How did I get HPV? 'Oral sex and probably open mouth kissing...'	Mmm... what's the real evidence for this? I just wonder if you need to find a way of explaining the collinearity effects and how individual sexual practice is difficult to quantify in terms of risk. Maybe a statement beginning, 'It would appear... however...?'
	3	Do I still have HPV? 'When cancer is caused by oral HPV has been treated, oral HPV is still found in some patients and not others'	What data is this statement based on?
	3	How did my HPV infection turn into cancer? 'Most infections go away on their own'	This fits with my previous point

	4	Figure 1	Maybe try and quantify in terms of most, many, few etc?
	4	Is my partner at risk of HPV? 'If you have been together for several years it is likely...'	Mmmm... most adults will not have active infection??
	4	Is my partner at risk of HPV? Cervical Screening	Why is this relevant here?
	4	Is my partner at risk of HPV? Condom use	I'm not sure there is any evidence for this in the case of OPC? Seems to be a bit of confusion with Cx?
	5	Will I get another cancer from HPV? Going for regular dental appointments	What's the evidence for this?
	5	Will I get another cancer from HPV? Going for cervical screening	Why is this relevant in this context?
	6	There is no need to change your behaviour 'Open mouth kissing might also be possible'	Evidence?
Health literacy academic	1	This booklet will help answer your questions about human papillomavirus (HPV) and how it is linked to oropharyngeal cancer. Oropharyngeal cancer is the medical term used to include cancers in parts of the mouth and throat shown in the picture below. In this leaflet we call it 'throat cancer' as you might know this word better.	This booklet will help answer your questions about human papillomavirus (HPV) and how it is linked to cancers in parts of the mouth and throat. The medical term is for these cancers is oropharyngeal (or-o-far-an-gee-al) cancer. In this leaflet we call it 'throat cancer' as you might know this word better.
	1	Diagram showing the parts of the oropharynx	Probably too detailed. A very simple sketch (without bone, muscle, sinus cavity) would do. Also it is not clear where the cancers live. Are patients told they have "back 1/3 of the tongue cancer"? Suggest very basic schematic showing only detail of cancer locations, and text of cancer names. e.g. tongue cancer – shade back 1/3 caption should explain what diagram illustrates

	1	HPV, or human papillomavirus, is a family of common viruses that live on our skin and the moist areas that line some parts of the body. HPV affects the:	HPV, or human papillomavirus, is a family of common viruses that live on our skin and moist areas of the body. HPV affects the:
	2	What is HPV?	Include skin in list?
	2		They are so common that everyone (?) has been exposed to one. Most people never have any symptoms. (?)
	2		Next sentence lists sexually transmitted/cancer causing HPV. Then table lists other kinds of HPV in other parts of the body.
	2		There are many types of HPV and most people have at least one type. Each type has a number. Some are low risk (do not cause cancer) and others are high risk (can cause cancer). In 20XX a vaccine to stop the most common HPV infections was developed. We hope (expect?) this will avoid HPV cancers in future.
	2	Most people	Everyone?
	2	Some are low risk...	What does low risk mean in this context? Low risk of infection or low risk of cancer? Risk concepts are often not well understood Confusing above. Is it just the 2 types that cause all HPV cancer? Or are they 2 examples of high-risk types? Also confusing if cervical cancer is caused almost always by these 2 types, or if there are non-HPV causes of cervical cancer?
	2	Almost all (90%) throat cancers caused by HPV are caused by HPV-16	Seems out of place here?
	3		Low-risk types can cause obvious symptoms Perhaps include this info in graphic above?

	3	All 12-13 year old girls are offered vaccination against HPV-16, HPV-18 (the high risk types), HPV-6 and HPV-11 (the low risk types) as part of a national school-based programme. Men who have sex with men aged up to 45 years are also offered the vaccine in clinics.	This does not flow from above...and is covered in last para
	3	HPV is passed through skin-to-skin contact with someone who has the virus. This can include genital, oral and anal contact. Oral sex and probably open mouth kissing can be risk factors for oral HPV. Risk of getting HPV goes up with the number of sexual partners a person has but you can get it from just one partner.	HPV is passed through skin-to-skin contact with someone who has the virus. This can include genital, oral and anal contact. Oral sex and probably open mouth kissing can be increase the chance of passing on oral HPV. You can get HPV from just one partner but the Risk of getting HPV goes up with the number of sexual partners a person has. Most sexually active men and women will come into contact with a high risk type of HPV at some point in their life. People with a high risk HPV infection usually have no obvious signs or symptoms.
	3	Just one partner	Ok phew I can relax
	3	Probably open mouth kissing	? Is it or isn't it?
	3	Risk of getting HPV goes up with the number of sexual partners a person has	The more partners you have, the more chance one of them will pass it on to you
	3	No obvious signs	"I didn't notice any warts..."
	3	It is not possible to know the exact time when someone got the virus. It can lie hidden for many years. You could have had HPV for years without knowing.	It is not possible to know the exact time when someone got the virus because it can hide in the body. You could have had HPV for many years without knowing.
	3	You could have had HPV for years without knowing	Is it always many years? Because if slow-growing, maybe I don't need to panic about it coming back?
	3	How did my HPV infection turn into cancer?	More logical directly under 'when did I get HPV?'
	3	Do I still have HPV?	And do I need to be worried that I will get cancer again?

	4	Do I still have HPV? When cancer caused by oral HPV has been treated, oral HPV is still found in some patients and not others. If HPV cannot be found it might be that it has gone away or you could still have HPV but your immune system is controlling it. There is need for more research in this area.	At this stage we don't know. Three things can happen: <ul style="list-style-type: none"> • HPV goes away • HPV hides from the test but stays in the body • HPV stays in the body and can be found with a test Your doctor can test for HPV, but sometimes HPV hides so the test can't find it. When cancer caused by oral (mouth) HPV has been treated, oral HPV is still found in some patients and not others. If HPV cannot be found it might be that it has gone away or you could still have HPV but your immune system is controlling it. We don't fully understand why this happens.
	4	Do I still have HPV?	These are quite complicated concepts. Rethink how to phrase this para. Some suggestions above
	5	Is my partner at risk of HPV?	Do we have prevalence estimates that you can illustrate with side-by-side icon arrays?
	5	Is my partner at risk of HPV?	Inserted: How can I reduce risk - rephrase to cover self, partners, others. How can people avoid HPV cancer?
	5	Is my partner at risk of HPV? It is important that all women aged 25-64 years go for cervical screening when invited to reduce the risk of cervical cancer.	Women aged 25-64 years should go for cervical screening to reduce the risk of cervical cancer. Is it free? Where do I get more info?
	5	Will I get another cancer from HPV? It is unlikely that you will develop another HPV-related cancer but it is hard to tell after treatment if the infection has gone completely. Your immune system could be controlling the infection. You can also stay healthy by: <ul style="list-style-type: none"> • not smoking • not drinking too much alcohol • eating a balanced diet • going for regular dental appointments • going for cervical screening (for women) 	This is another complicated concept This para is about taking care of your health to support your immune system It is unlikely that you will develop another HPV-related cancer even if the virus stays in your body. Here are some things you can do to stay healthy: <ul style="list-style-type: none"> • don't smoke • limit alcohol to 2 drinks per day • eating a balanced diet • going to the dentist twice a year • going for cervical screening (for women) every 2 years
	5	Your immune system could be controlling the infection	Meaning? This is another complicated concept
	5	Not drinking too much	Or recommended amount

	5	Eating a balanced diet	What does this mean? Equal amounts of meat and potatoes? Fish and chips?
	5	Should I be vaccinated against HPV?	Vaccine is a new concept here. Perhaps a section with overall heading about preventing HPV cancer, and subheadings on healthy living, screening, and vaccines? Quite unclear
	6	Should I be vaccinated against HPV? As a large number of HPV-related throat cancers are caused by HPV-16, researchers are hopeful that vaccinating children now will protect them against HPV-related throat cancers in the future.	Too complicated. Basically – we have a vaccine, we don't know yet if it works for throat cancer (but we think it should). We do know it works for cervical cancer
	6	Should I get my children vaccinated against HPV? The NHS recommends that girls are vaccinated against HPV. The vaccination has not yet been recommended for boys in the UK, but men who have sex with men who are aged up to 45 years can get the vaccine in clinics.	The NHS recommends that girls are vaccinated against HPV. Men aged up to 45 years who have sex with men can also get the vaccine in clinics. Does this mean it is free? What if my girl is already 16? Can I get my boy vaccinated if I pay for it?
	6	Men aged up to 45 years	Assume this refers to person seeking vaccine, not their partner?
	6	HPV is normal	HPV is common?

7	<p>There is no need to change your behaviour</p> <ul style="list-style-type: none"> • Risk of oral HPV increases with the number of sexual and oral sex partners you have. But some people get HPV with only one sexual partner. • Getting HPV through open mouth kissing might also be possible. • You could not have stopped yourself getting HPV so there is no need to change your sexual behaviour. • Most people will probably get oral HPV at some point in their lives. It is very unlucky when this turns into cancer and we do not know why some people get cancer and other people do not. <p>Nobody is telling you to change your sexual practice but using condoms for all sexual behaviours, particularly with new partners, could give you and your partner some protection against genital HPV</p>	<p>There is no need to change your sexual behaviour</p> <ul style="list-style-type: none"> • Most people will probably get oral HPV at some point in their lives. It is very unlucky when this turns into cancer and we do not know why some people get cancer and other people do not. • Risk of oral HPV increases with the number of sexual and oral sex partners you have. But some people get HPV with only one sexual partner. • Getting HPV through open mouth kissing might also be possible. • You could not have stopped yourself getting HPV so there is no need to change your sexual behaviour. • Nobody is telling you to change your sexual practice but using condoms for all sexual behaviours, particularly with new partners, could give you and your partner some protection against genital HPV.
7	<p>Nobody is telling you to change your sexual practice but using condoms for all sexual behaviours, particularly with new partners, could give you and your partner some protection against genital HPV.</p>	<p>This sentence is complex and a bit contradictory. I'm not telling you what to do... but wear a condom!</p>
7	<p>There is no need to change your behaviour</p>	<p>There seem to be some contradictions in this paragraph.</p> <p>Also this is for a person who has had HPV cancer.</p>
7	<p>Outlook</p>	<p>5 year survival, size of tumour, risk of metastasis.... Could mean so many things</p>
7	<p>Better</p>	<p>This is a relative term and a bit meaningless. Yes you have a disfiguring cancer But it could be worse!!</p>
7	<p>Treatment</p>	<p>Is there positive news about the treatments? E.g. targeted therapies?</p>

	7	Websites	More context would help. Or can you put them next to relevant text?
	General		Know when you are informing vs instructing. Make sure the language matches your intent
	General		Perhaps a section on things we don't know? There is quite a bit of hesitant language, which people find confusing, and healthcare providers might find difficult to explain
	General		Vaccine section looks like you can only get it if you are 12-13f or <45msm. Which seems a bit odd (and the reasons for this are complex to explain). Does NHS limit prescriptions to only those groups or just recommendations/funding?
	General		Reassurance section is not very reassuring. It is a bit confusing and in some places contradictory. Might be better as just a list of known facts? E.g. 1. you can get it from one person, 2. vaccine might prevent it, 3. condoms can help but not completely, etc
	General		Can you leave the choice about changing behaviour to the individual? Or refer them to sexual or other counselling service? There might be guilt, shame, etc...I can't see that any leaflet can really address those feelings. Suggest talking to partner about any changes to sexual behaviour? Partners are reading this leaflet too and may need help
	General		Also if they smoke, they should stop! No debate, right? There are other lifestyle behaviours they may want to change – cancer diagnosis can be a crisis point for people to change their lives. Can they talk to their GP about this, or are there other services available?
	General		How well understood is concept of “immune system” by lay people? How else can you explain this?
	General		Be wary of vagueness e.g. “don't drink too much”. What does this actually mean? Give people information they can act on. You could also present lifestyle tips as an attractive graphic (making sure that the meaning is obvious from the picture and you are not relying on words to qualify)

HNC Speech and language therapist	1	call it 'throat cancer' as you might know this word better	Maybe could change this to 'In this leaflet we will simply use the term throat cancer ... original may sound patronising to some people. I have a slight concern that people may think that the larynx cancer (more commonly what we (clinicians) may call throat cancer) is also a result of HPV... but I can see that you are trying to find one word that's not too technical. Not a biggy.
	2	Can they cause cancer? (figure)	Could this be 'which types cause cancer?'
	6	Nobody is telling you to change your sexual practice but	Not sure we need this bit
	6	Compared with head and neck cancers caused by smoking and drinking alcohol the outlook for patients with HPV-related throat cancers is better.	It may be worth sounding this out on a few people to get the wording right/precise. HPV may co-exist with smoking, and outlook is affected by several other factors too.
	6	This is good news. HPV-related throat cancers respond better to treatment.	This is good news. HPV-related throat cancers tend to respond better to treatment – this may therefore provide a better outlook than head and neck cancers that are linked to smoking and alcohol use.
	6	This is good news.	I am a bit cautious about the "good news" - My PPI group think that getting cancer can never feel like good news, so being told that your cancer may respond better and therefore this is good news may be construed differently by different patients. Might be best to keep to fact.
Academic behavioural scientist	2	Most sexually active men and women will come into contact with a high risk type of HPV at some point in their life. People with a high risk HPV infection usually have no obvious signs or symptoms. All 12-13 year old girls are offered vaccination against HPV-16, HPV-18 (the high risk types), HPV-6 and HPV-11 (the low risk types) as part of a national school-based programme. Men who have sex with men aged up to 45 years are also offered the vaccine in clinics.	Maybe list under a subheading: 'how many people get HPV?' Where it sits currently feels a little disconnected.

	3	When did I get HPV? It can lie hidden for many years	Would 'stay' be better term?
	5	Should I get my children vaccinated against HPV?	Have you considered adding a sentence explaining that girls are vaccinated at 12-13 to achieve the best immune response as this is when their immune systems are developing rapidly.
	5	Should I get my children vaccinated against HPV? Figure	Might rethink the presentation of this info. I worry that people will confuse the message about vaccination and read 12-13 year old girls having sex with men.
	6	There is no need to change your behaviour: Risk of oral HPV increases with the number of sexual and oral sex partners you have. But some people get HPV with only one sexual partner. Getting HPV through open mouth kissing might also be possible	This loses the message that HPV can be transmitted through skin to skin contact not necessarily bodily fluids
	6	Most people will probably get oral HPV at some point in their lives. It is very unlucky when this turns into cancer and we do not know why some people get cancer and other people do not.	Most people will probably get oral HPV at some point in their lives. It is very unlucky when this turns into cancer and we do not know why some people get cancer and others do not.
	General		Think a glossary of terms might be helpful to include with a list of all the medical jargon words defined. I'd include in that words like verrucas, genitals, etc.
	General		The section on should I get my kids vaccinated might benefit from a sentence explaining the rationale for vaccinating at the onset of puberty, i.e. To generate maximum immune response to vaccine.
	General		I haven't commented in detail on the 2nd and 3rd figures, but I found them a little more difficult to process. But I'm assuming that you will get graphic designer to help with that?

APPENDIX 9.3: STUDY 6 – FEEDBACK FROM PATIENTS

Comments	DS (Male)	DK (Female)	TB (Female)	TR (Male)	MT (Male)
Overall impressions	Thanks for sending me this brochure. It is extremely good, I wish my wife and I had access to this when I was first diagnosed. I think this brochure is excellent, and will be very useful for people diagnose with these cancers, and for their family and friends.	Excellent to have a resource, I would have found this really useful at the point of diagnosis, especially to share with family as HPV related cancer is very difficult to talk about, especially with children and older relative. I didn't share the specific details of my cancer for exactly this reason.	I loved the leaflet, I feel you have included every detail required for a newly diagnosed patient.	I find your leaflet to be reasonably attractive and very organised. The color scheme could be a little more colorful, in my opinion. But, I am a graphic artist and enjoy a more vibrant color palette.	I need to know who the leaflet is aimed at to do this properly. Is it post-diagnosis or post-treatment patients? Or others? Better than other info I was given. Straightforward explanations. Not too scary.
The use of the language used in the leaflet/is it written in words you can understand	The language used is fine, it was an easy read without the use of medical terms or being overly verbose. (I also liked your guide on how to pronounce "oropharyngeal", it is hard not to sound like an idiot trying to repeat that word the first time you hear it)	Good use of plain English, nice tone, easy to read but gives a sense of being very professional. The only part-sentence I was a little uncomfortable with was "You're not responsible for your throat cancer" - I would have preferred it to say something more along the lines of 'getting cancer is not a result of your behaviour' - but I'm still not sure why this sentence bothers me...		The use of the language in your leaflet is very easy to understand and answers most, if not all, the questions I would have if I was concerned about the HPS viruses and their association with throat cancer. I do like the way the brochure is laid out.	Yes

Comments	DS (Male)	DK (Female)	TB (Female)	TR (Male)	MT (Male)
The order of the information presented	The order of topics correlates with the order of the questions is likely to ask.	The 'Things to remember about HPV' was a really useful reminder, but some of the information could helpfully be repeated in the body of the document. The most important phrase for me was "Having HPV is a result of normal sexual behaviour" - I think this should really be in the 'How can HPV be passed on' as the first line - or even the heading (replacing 'How can HPV be passed on')	It's well organised and the order of info is correct, detailing the statistics, complete with diagram etc		Start with (viral?) cancer, then talk about HPV?

Comments	DS (Male)	DK (Female)	TB (Female)	TR (Male)	MT (Male)
The use of headings throughout the leaflet	The headings help you zoom in on the topics making the leaflet a useful reference guide.	Aside from comment above, headings were helpful. My only critical comment would be that where a question is posed, it is not really answered. For example, 'Should I be vaccinated..' has information about vaccination for women, men over 45 and does not really give me an idea of whether I can or should be vaccinated. The 'What types of HPV can cause cancer?' heading is not really relevant as it doesn't say which types of HPV cause what - it lists high risk and low risk things - HPV related cancers are high risk HPVs? Are warts etc type of HPVs? Found this a little unclear.		I do like the headings. They are a nice size and the font is easy to read. I would make all headings flush left instead of making some centered and others flush left. I just like consistency.	Fine
Whether the diagrams are easy to understand	The diagrams do the required job, I prefer the pie chart to the pyramid on page 12.	The only one I found a little tricky to understand was the MANY YEARS diagram. I found the pie chart easier to visualise.	I think both pie chart and pyramid are effective and explanatory	I like page 13 better than page 12.	Yes

Comments	DS (Male)	DK (Female)	TB (Female)	TR (Male)	MT (Male)
If the leaflet covers the things you feel are important	Yes, I can't think of anything missing	Apart from its own unanswered questions		I feel you were pretty thorough in describing how HPV is transmitted. You might consider some symptoms people may look for to ascertain whether they may need to be checked for throat cancer.	
If there is any information missing that you would have liked to be included	Links on page 16 could include reference to: www.mouthcancerfoundation.org and www.oralcancer.org (Very technical with lots of medical research info) The link on page 16 to Cancer Research UK: http://goo.gl/96Ppcv may have been replaced by http://www.cancerresearchuk.org/about-cancer/causes-of-cancer/infections-hpv-and-cancer/hpv-and-cancer	Not quite sure why the help yourself box next to 'Will I get another cancer..' mentions dental checks, but not regular follow-up oncology checks (especially as a great number are not visible in the mouth by a dentist)	You have mentioned how treatable this type of cancer is but not exactly what the treatment is. I understand it differs per patient and this leaflet is an explanatory leaflet regarding HPV, if I had any comments it would be to mention radio and chemo but I understand why it's not.	One thing I think would be beneficial would be to list the types of HPV that are not high risk types for HPV. I had HPV 16. That is a high risk HPV type. You might want to consider listing the low risk types.	More vaccine info More detailed explanation of what HPV is Differences between viral and genetic and other types of cancer Can I get any test to see if I still have HPV Implications for children. Do they have a propensity for this type of disease? More info on the different types of cancer associated with HPV Info around lymphatic system, nodes etc. Likely treatment Long term implications of treatment and things to do to combat them

Comments	DS (Male)	DK (Female)	TB (Female)	TR (Male)	MT (Male)
Is any of the information unhelpful	No, there is nothing unnecessary here. I'd think most people would want access to as much information as possible when they are trying to understand what a HPV Throat cancer diagnosis means.			I think all of the information is very helpful. I like the leaflet very much. I think it just needs a little more information, which I have mentioned.	No
Is any of the information unnecessary	No, as per my last answer				No
Any other comments/ changes you would like to see	My only negative criticism is in the 'Should I be vaccinated' section. The second last sentence states "We don't know for certain whether the vaccine prevents throat cancer – researchers are still working on this". This doesn't make sense to me. If the vaccine had prevented me from getting the virus I couldn't have got an HPV cancer, what further research needs to be done? Are they saying that the vaccination only works for women and gay men? If heterosexual men aren't getting vaccinations offered to them, I assume that the incidence of HPV cancers in men is lower than in women and gay men, so it isn't seen as economically worthwhile.		Other than that, it's perfect! I only wish it was available to my husband and I when I was diagnosed! We perhaps wouldn't of relied on google and read info that made our relationship suffer in the first couple of weeks until my planning appointment at the cancer centre. At this appointment we were then informed of all the contents of this leaflet. A very big well done to you! ☺ publish it soon!!		

Comments	DS (Male)	DK (Female)	TB (Female)	TR (Male)	MT (Male)
Cover design	6, 9, 4, 1, 10, 5, 8, 7, 2, 3 I would have thought that the majority of people being diagnosed with these cancers will be middle aged men. This demograph doesn't seem to be represented on many of the options. (I'm not being sexist here, my wife mentioned this before I did!).	4; 3; 2; 10; 5 ;7; 1; 6; 8; 9	1, 6, 4, 7, 2	4, 3, 5, 7, 2, 1, 9, 10, 6, 8	3, 2, 6, 5, 4, 7, 9, 8, 10, 1